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ABSTRACT

The monograph describes the pursuit of change undertaken by a voluntary parent and community association for the purpose of modifying attitudes and services which were felt to be critical, lacking, and necessary to the benefit of mentally retarded individuals and their families. A discussion of the 5-year program includes theories of change, the community setting, the methodology of the project writing staff, a descriptive analysis of selected sub-projects, and analyses of the process and pursuit of change. Appendixes provide additional data concerning the project and the Kennedy Center in Bridgeport, Connecticut. (RD)

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THE PURSUIT OF CHANGE

Experiences of A Parents' Association

During a Five Year Program Development Period

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FINAL REPORT

Project - RD - 1435 G

**PARENTS AND FRIENDS OF MENTALLY
RETARDED CHILDREN OF BRIDGEPORT, INC.**

THE PURSUIT OF CHANGE

Experiences of A Parents' Association
During a Five Year Program Development Period

by

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Parents and Friends of Mentally
Retarded Children of Bridgeport, Inc.

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P R E F A C E

This monograph describes the pursuit of change undertaken by a voluntary association, the Parents and Friends of Mentally Retarded Children of Bridgeport, Inc., on behalf of the mentally retarded of that community.

It concentrates on the activities of a federally funded Project during the years of its life. That Project took place during a period of rapid change on the national and international scene. New legislation, developing conceptions of opportunities for the mentally retarded and the handicapped, the rise of new agencies providing or sanctioning improvement in services, shifts in the programs of state and national associations, and disruptive world and national events, mark this period.

Given this, the effort to describe a single change sequence in a particular community of one state was undertaken. The understanding of change on what is relatively a small scale is essential for comprehension of large scale changes.

This monograph attempts to add to man's knowledge of how change occurs and of how it is attempted.

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CHAPTER I

THE THEORY OF THE PURSUIT OF CHANGE

This report attempts to answer the deceptively simple question: What did the Project accomplish? It is deceptive because as one considers how to answer it, other series of questions quickly come to mind.

One series of questions concerns what would have happened in Bridgeport, if the Project had not existed. Changes in cultural attitudes, services, and facilities for the retarded taking place in other areas throughout the period of time covered by the Project undoubtedly affected this city. In fact, the Project itself may have been, in effect, an important manifestation of that change. Whether it was or not, a significant question is whether the changes that may have taken place in Bridgeport paralleled, followed, or led the changes that took place in other areas of the country.

This brings up the question of what changes are taking place or have taken place in America as a whole. Many people believe that changes of some magnitude, generally considered "improvements", have been taking place. Assuming that significant changes have occurred in the United States, can we assume that these changes have been uniform in different communities? Certain communities may pioneer, others may quickly follow upon changes initiated elsewhere. Some may serve as models for change; others may attempt to serve as such models.

One relevant question is whether the very attempt to serve as a model results in the communication of viable ideas to others, ideas that have some significant influencing on other organizational and community settings. Specific, planned efforts at communication, as well as more casual and informal influences, must be carefully analyzed before one can state categorically that a self-designated pioneer in behavior proved, in fact, to be a pioneer.

Other communities may choose to follow the lead of pioneering communities. Some change independently and because of local pressures pursue an independent track. Some changes may be in line with overall national trends, or at least parallel what is innovated elsewhere, while other changes may diverge significantly from the prevailing patterns.

Finally, of course, are those organizations or communities where little change, or at least little planned change, occurs. These are the "static" communities or settings, those that are well-established and self-supporting, where mutually satisfactory exchanges of resources and services exist between the organization that provides services and the larger community which provides resources. On a larger national, state or regional scale, these may be viewed as resisters to changes that are proven or established elsewhere.

Understanding what has changed in Bridgeport during the five years of the Project is clearly a complex problem. Equally complex is the fundamental question about the effects of the Project. To determine the degree to which the Project acted as a pioneer, we must understand what it originally set out to do.

What changes were projected as the outcome of the Project? Which goals were considered major and which minor? Were certain changes, transformations, enhancements, and innovations projected as targets for the first, second, or third years, or perhaps for the fourth or fifth year? Others may have been targeted only for occurrence after the earlier achievement of other changes. This raises the question about the interrelation of the dimensions of importance and of timing. What was the projected chronology of these goals, and which were prerequisites for others? To what extent did the importance assigned to each determine its timing?

Highly important goals may be emphasized in a proposal for change that also includes a series of proximate goals of lesser assumed significance. The proximate goals may be more realizable, more tolerable to the other organizations and agencies who must be involved in the transactions that occur in the pursuit of change. The pursuit of change may require a complex classification of goals by priority and by timing. It also may entail a balancing of the beliefs and needs of the many different individuals and sub-organizations involved in change. Such a balance may evolve harmoniously, in strife, or, most likely with a mixture of harmony and strife.

Goals for change projected by a group often focus on influencing other groups. Getting others to modify their behaviors by addition, deletion, redirection, by renewal or the devotion of increased or decreased effort, by placing existing activities into a new sequence of events so as to create new links, or by changing the sequence of events that follow current behaviors all these are common and everyday efforts in virtually all social systems.

Goals for change are formulated differently of course, by different groups. Although sponsors of change may agree among themselves about the scope of changes, dissensus can and often does exist. The formulations of goals by sponsors may concern the enhancement of existing activities and the creation of additional activities by themselves and by other organizations. Discord and disagreement about what changes are needed, and, if needed, are possible, often arise.

The goals for change in this instance comprises a four-part system consisting of (1) formulations by sponsors of ways in which (2) other elements of society, including organizations and agencies, both public and private, could be changed so as to engage in (3) new or changed activities or behaviors and "services" that are deemed critical, lacking, or simply socially and humanely appropriate for (4) mentally retarded individuals and their families within the community. These, then, were goals by one group that involved changes that others were to undertake for the benefits that would presumably accrue to still others.

In the pursuit of change, resources are committed. These resources may be systematically arrayed and organized on the basis of the outlined statement of goals and the formulation of procedures, mechanisms, and strategies that normally are included in a pro-

posal for the pursuit of change.

A critical question is whether the resources committed to the pursuit of change are adequate in amount to the task. The resources may be narrowly viewed as mainly financial, but even the use of funds requires the existence and recruitment of individuals, groups and organizations ready and capable of using such funds adequately for the projected goals. It must be determined whether these resources are sufficient, excessive or inadequate to the changes envisaged.

Another vital question concerns the organization of resources. Is the manner in which they are expended likely to be the most effective for the goals of change? Are the available skills and capabilities, whether of individuals employed directly in the change effort or of those whose affiliations are with other organizations or groups, useful for the objectives of the change proposal? Is there an effective division of labor within the change group?

We must add as well, the general question of the quality of interaction between the host or sponsoring organization and the implementing groups. Sponsors may take fledglings under their wing, supply resources, and define objectives. Implementers may initially accept the role outlined for them by sponsors of change, receive resources, and accept objectives. But as the implementer group evolves and is strengthened, interaction with sponsors may change character. The implementers come to initiate ways of defining situations. For example, they may request redirection or re-organization of resources, perhaps re-allotments of funds. They may pattern programs on the basis of experience, education, and occupational and professional perspectives. These may entail re-assessments of priorities placed on goals, and re-evaluations of the goals themselves which were projected for them and to which they were committed by the sponsors.

The transactions may shift as follows: their goals lead the sponsors to recruit additional individuals to help them implement their goals. These individuals cluster. They accept resources, such as funds, space, facilities, equipment, and supplies. They come to modify goals, acting, at first, within the framework of the goals set by the sponsors but conceivably later, through interaction and communication, modifying, evaluating, and recasting those goals in terms of their own emerging priorities.

A related and fundamental point concerns the scope of change. When proposals for change are developed, the range of ingenuity of the human actors involved, as well as their perceptions of the systems for which the proposal are relevant, determine the content and the substance of the proposals. In this sense, proposals for change stand by themselves as items for analysis. The analysis of the proposals may start with the attempt to judge the degree of their understanding and the quality of their perceptions of the community and its various systems. The manner in which people perceive the community obviously affects the manner in which they seek to change it.

Many questions may be asked about the perceptions of the community and about the formulations of how to change the community. One broad area of questions concerns the level of understanding of the nature of community and the inter-relationships of institutions, such as the family, education, government, religion, work, and the like. At

both verbal and operative levels, individuals involved in the pursuit of change may focus their efforts on particular individuals who wield power through the institutions and organizations with which they are associated. Influencing or hoping to influence other agencies, including those that have a broad service function in the community, may occur through joint meetings with their officials or executives, members of advisory boards, governing committees, and the like. Working with key individuals and units or sub-units with manifest authority and power, is a standard strategy in the pursuit of change.

This strategy aims to develop working relationships that entail commitments by organizations. Such commitments may be only verbal, but they may also lead to action, be continuous and of long duration, or attenuated and more limited than initially contemplated. Termination of actions may also occur.

Terminations or attenuations in actions implied by verbal commitments often occur when expectations clash. Particularly when two or more organizations are involved in some program for action, the probability of a commitment not being followed up for a long period of time or exactly in the manner expected is rather high. A proposal greatly valued by one organization may not be given especially high priority by another. A special focus agency or organization may deal with general purpose organizations whose obligations for action reflect the support and sanction of elements in the community unsympathetic to the programs of the special-focus agency. This may make unstable any commitments for working relationships.

Another broad question concerns the understanding among the change sponsors of the cultures both of the other organizations and of the broad community. In this instance, one may ask what were the beliefs and perceptions toward the retarded, the socially deviant and the socially malfunctioning, both within the community as a whole, and within the key agencies and organizations?

A further relevant manifestation of the culture of the community concerns the extent of resources, professional and financial, that are allotted to the various organizations for their programs. These may be allotted differently, depending on whether the organizations are trying to change the community or are trying to implement what the community wants.

Authority is also a key to the understanding of change. The functions of an organization reflect whether it is part of the government, either local, state, or national, or whether it is a voluntary or private agency. Assuming for the moment that the estimate of gaps in activities and needs for services is accurate, and assuming further that the expressions of this estimate are good reflections of people's beliefs and values, one must still determine the nature of the organizations espousing these ideas.

In this instance, the organization espousing ideas for change was a voluntary association of individuals with common special interests in retardation. The local schools, and other related agencies of local and state government, are public agencies, providing services to the public at large. Their authority derives from the sanction and support of the establishing legislative bodies. Their actions promote, or are supposed to promote, the general welfare of the entire community.

The transactions between the voluntary special interest association and the government agency or agencies can, therefore, be viewed as bringing together (1) an organization with limited, focused goals reflective in large part, of the interest or "needs" of its members and with authority based on society's tolerance for special interest private associations, and (2) organizations with goals broadly sanctioned by the bodies that are representative of the general community and engaged in actions presumably calculated and planned so as to serve the common interests.

Change, of course, is rarely total. Those who project total alteration of existing systems are revolutionaries who generally focus on political institutions. Their success or failure depends on the nature and breadth of their support among the general population, on their leadership in moving toward their goals, including the overthrow of the existing system, and the duration of the new system once it is established.

Proponents of total change often describe, and sometimes attempt to enact, utopias. All or most blueprints for change involve a utopian vision. They often portray in writing, in sermons, or in other verbal presentations, some new system of interpersonal interactions, some new moral code.

Such social utopias generally include (1) an appraisal of the current role assigned by society to a particular category of individuals, (2) determination that those roles are inadequate, that role incumbents are stigmatized, handicapped, and not permitted to enjoy the fruits of society, (3) a series of projections of idealized roles for those individuals, emphasizing mainly how they should be treated, and (4) a prescription for efforts by government and other agencies to implement these new roles for the disadvantaged.

The Association formulated such a utopian sketch in its pursuit of changes in treatment of the retarded. The sketch reflected the beliefs of parents that mentally retarded individuals in Bridgeport were not adequately able to develop to their full human potential. Schools, recreational facilities, employers, health and welfare institutions, did not welcome the retarded. Parents suffered virtually the entire burden of care, unless they chose to have their children admitted to state institutions, and from their own or friends' experiences, they believed that a lifetime burden of responsibility rested upon their shoulders. Stigma, rejection, isolation, emerged. Dependency and possibly abuse were common.

In contrast to this, parents visualized a broad set of changes as desirable. Schools would adopt programs to the individual needs of the handicapped youngsters, special diagnostic facilities would be established, recreational programs could be initiated, sheltered workshops and occupational training programs would make it possible for some to prepare in appropriate ways for employment suitable to their capabilities, necessary medical and nursing programs would be enhanced or created, and locally-situated residential centers would be initiated.

Funds would be sought from all quarters, locally, within the state and ultimately from the federal government, as would commitments from a wide range of public and private organizations to open their doors to the retarded. New programs and new facilities were to be initiated.

The short-run aims were to remove or reduce the stigma, to replace rejection with acceptance, to substitute involvement for isolation, to avoid dependency, and to eliminate abuse. The longrun aim was to enhance the independence of the retarded and to have them win acceptance within the community as a whole.

The utopia on which the pursuit of change was based ultimately came to rest on a Project supported by federal funds. It is that Project which is the center of this study, which concentrates on the years from 1963 to the present. Prior years saw, however, many dramatic changes in the community which furnish the backdrop for what took place later.

The first phase began with the 1951 establishment of the Parents and Friends of the Retarded, and its efforts to have the City of Bridgeport establish special education programs for the trainable retarded. The Association soon became involved in young adult recreation programs and with a day camp program; with trying to encourage the development of scout troops and with an adult night school.

As this first phase continued, those active in the Association began to believe that additional services were needed and that these could best be provided by the construction of a building to house these services. This led to a new development which was embodied in planning for a building on William Street in Bridgeport. The Association joined the United Fund in 1955, and hired its first professional employee about that time. In 1956, programs started at the William Street building which was known as the Kennedy Center.

According to one observer:

When the Center opened it was the first of its kind in the State. Consequently, we had to find our way by trial and error. Nevertheless, programs developed rapidly. We became very proficient in running day camps, scout troops, public speaking and education programs, our work-shop, and above all, in scrounging help and equipment from community sources.

Few professionals were available in the early days. Resources were limited. Consequently, parents bridged the gaps that today would be filled by professionals.

Kennedy Center was born, said that observer, "...seventeen years ago of the need parents felt to help those retarded children who could not go to public schools."

In 1956, a clinic program run on a volunteer basis, was opened at the Kennedy Center, housed at the building on William Street. Clinic functions were performed by a physician-surgeon, pediatrician, and a psychologist who provided services at no cost. Laboratory services were provided. The Clinic functions developed further to include a dentist, speech therapist, social worker, vocational counselor, and a number of medical consultants. All known or suspected mentally retarded children and adults were first seen at the Clinic as a basis for placement in the appropriate Kennedy Center program.

The pace of events during that time was recently described by the current Executive Director as follows:

Counseling new parents, running recreations programs, fighting for progressive legislation, dealing with the community and the constant raising of funds, kept parent volunteers busy every spare moment.

With all these efforts, further changes were almost inexorable, and these were summarized succinctly by the Director as follows:

It soon became clear that with all the programs and activities that Kennedy Center was involved in, we had outgrown our physical plant on William Street. A huge fund raising campaign was launched and with membership pledges, pledges from outside sources, and a construction grant from the government, we built the Kennedy Center on Virginia Avenue. The result in 1964 was a \$450,000 building...

In 1963, we received a Grant to Demonstrate Comprehensive Community-Based Services for the retarded.

How the Project supported by that grant engaged in the pursuit of change from 1963 to the present is the focus of this monograph.

The Project's activities were numerous and complex, and the pace of its efforts rapid, especially during the first two or three years. An understanding of what is accomplished requires examination first of the community setting. The following chapter concentrates therefore on the City of Bridgeport itself. The Project as an undertaking is then reviewed, by means of summaries of the Proposal which the Association prepared and for which federal funds were awarded. Following this, the methodology of the "Project Writing Staff" which prepared this monograph is presented.

Presented at the outset, these materials are intended to place emphasis on events since 1963. With that completed, we then turn to the years prior to 1963 in order to highlight the manifold efforts of the Association and the changing geographic settings within which its activities took place. This background is essential for analysis of what occurred later.¹

From this, we provide a detailed analysis of what will be called sub-projects, that is, specific undertakings embodied in the overall Proposal for the Project.

The succeeding section comprises chapters dealing with the delivery of services to needs, conflicts that affect change, the functions of the volunteer parent association in producing change, and issues involved in change.

¹ Various histories of the Association and of the Project have been prepared at different times by or for the parents' group in Bridgeport for purposes of self-review or fund applications. These secondary accounts highlight in changing perspectives what has taken place in the last decade and a half. Several are presented in the Appendix to this monograph.

A concluding chapter returns to the opening question of this chapter, "What did the Project accomplish?"

CHAPTER II

THE COMMUNITY SETTING

Bridgeport is, in most respects, like many other American cities. It is presently beset by the very same kinds of social changes which characterize other modern cities: it is experiencing a large influx of non-whites, the suburbs around the core city have grown in population, and the retail merchandising of the region is becoming decentralized in suburban shopping centers.

The City of Bridgeport has developed in the course of three hundred years from a coastal settlement to the dominant centralized city in its region. From 1800 through the end of the century, its growth in population far surpassed the other original settlements in the region to an extent described as "phenomenal".¹ From a population of 2,800 in 1836, it rose to 143,500 in 1920 and then at a much slower rate of growth to 159,000 in 1950. This was a point of stabilization for the population dropped back to 157,000 in 1960 from the peak recorded a decade earlier.

The city's population grew during the nineteenth and early twentieth centuries largely because of immigration. According to one account,

...wave after wave of immigrants followed the early English settlers. People of Irish descent began to arrive in 1845, Germans in 1848, Polish in 1861, and the Hungarian, Italians, Greeks, Armenians, and Albanians around 1900. Many of them settled in a particular neighborhood near their former neighbors or new friends who spoke the same language and thus aided one another. Many of their native customs, shops, churches and habits were retained and provided a rich source of cultural heritage for the Region.²

A key feature of the currently relatively stable population of the city proper is that the "mix" continues to change. In 1950, about 4% of its population was non-white. This comprised about 90% of all non-whites in the region in which it is the dominant urban center.

¹ Greater Bridgeport Planning Agency, Inventory of Regional Resources, August 1962, p. 4.

² Ibid, p. 5.

This segment of the population tends to be in different circumstances from the other components of the community. In 1960, some 43% of non-whites were under 18 years of age, while 30% of the whites were in the same age category. About 15% of the non-white women were separated or divorced, compared with 5% of their white peers.

Another population component, Puerto Ricans, have come to Bridgeport in large numbers in the last decade or so. These last arrivers are very young compared with the remaining population: their median age was 18 in 1960, while that of the region as a whole was 33. The large influx of Puerto Ricans brought the numbers of that group to 6,000 in 1960 in the Standard Metropolitan Statistical Area.³ About 1/3 of the state's entire Puerto Rican population resided within the city.

The year 1920 proved to be something of a turning point in population growth for the city proper. By then, "the city was virtually filled to capacity...."⁴ The suburban towns of Easton, Fairfield, Monroe, Stratford and Trumbull began to increase rapidly in population to the point where they are ten times as large in 1960 as they were in 1900. In the same sixty years, the city proper has merely doubled in size. By 1960, its population was but 56% of the regional total.

Migration has been the major process at work, one of greater importance than births and deaths. According to the recent Planning Agency survey,

The towns have been a net receptor area, principally of whites, but also of a few non-whites. The city, meanwhile, has been a receiver of non-whites but a dispenser of whites. On balance, the region has gained a large number of young persons, both white and non-white. It has gained greater numbers of middle aged and older non-whites, and has lost moderate numbers of middle aged and older whites...⁵

The particular migratory processes in operation have further altered the composition of the city's and the region's population, in ways likely to increase the incidence of retardation and perhaps to decrease its recognition as a social problem. A failure or hesitation by recent immigrants to adopt urban patterns, to be able to cope smoothly and effectively the urban requirements of large schools; to overcome impersonality, alienation, and new and often confusing social norms and complex organizations; or to understand such an environment

³ This includes suburban towns of Milford and Shelton along with the Greater Bridgeport Region's components of Bridgeport, Stratford, Fairfield, Easton, Trumbull, and Monroe.

⁴ Greater Bridgeport Regional Planning Agency, Housing In The Greater Bridgeport Region 1960-1980, Trumbull: July 1965.

⁵ Housing in the Greater Bridgeport Region 1960-1980, pp. 3-4.

at least at first, often overwhelms new immigrants. A manifestation may be loss of employment and school failure or dropouts by children.

The existence of the migratory processes underlying such phenomena in Bridgeport may be known in part to many of the area's citizens, the organizations that serve or exploit them, and the associations they form. The individuals involved may see local neighborhood changes or moves, and generally be aware that changes of similar character are occurring in various parts of the city.

That these changes are critical for understanding the life and culture of the entire community, the challenges that confront it, and the deficits or gaps in activities that exist may be surmised by some, but is not often fully appreciated. How such events are, for example, related specifically to the Project and what happened during its span of existence may not be understood or fully appreciated even by the actors themselves.

A succinct summary of dominant factors of migration significant to this Project and the events associated with it is provided in the July 1965 Housing Study of the Planning Agency, as follows:

In both the city and suburbs, almost half of the 1960 population had moved at least once since 1955. Some of these moves were from suburbs to city, and many others were intra-city and inter-suburban in character. It is abundantly clear, however, that most of the new residents of the city are Negroes and Puerto Ricans who previously resided in the South and elsewhere beyond the region, and that the new residents of the towns are whites (other than Puerto Rican) who moved from the city or directly from outside the region.

Adjustments to arrival in the city involve difficulties in moving into system-defined roles, and this remains a common problem in Bridgeport. Thus, in its Regional Profile... Bridgeport Region, the Statewide Planning Project for Vocational Rehabilitation Services⁶ writes:

Just over half of the Bridgeport District's non-agricultural labor force works in non-manufacturing occupations. The only substantial unemployment in the Bridgeport District is in Bridgeport. This problem is aggravated by the out-migration of the white middle and lower classes and the in-migration of Negroes from the deep South, Spanish-speaking people from Puerto Rico, Jamaicans, and Portuguese. Many of the migrants coming into the area are characterized by lack of education, lack of marketable skills, lack of long-range career goals, and unawareness of the community resources for self-help. [*italics added*] The remainder of the Bridgeport District is quite economically stable and has low unemployment. The manpower problem in the entire area is a shortage of available applicants who are qualified for available positions. There is a healthy growth of jobs in the district.

⁶ Undated report, probably 1966, mimeographed, p. 4.

Schooling, jobs, and access to resources for self-help were, therefore, major problems confronting the new additions to the city's population.

The manifestation in jobs was described in the useful compendium, Inventory of Regional Resources,⁷ which reports that

There is also an indication that unemployment in the unskilled labor force has been increasing, while the skilled and the semi-skilled show a lesser degree of unemployment. This fact may indicate signs of "structural" unemployment requiring "specialized" efforts such as re-training, vocational education, re-direction and correction of the school drop-out situation.

Another description of significant recent change, from 1950 to 1960, is "...a great increase in professional, technical and clerical employment and in craftsmen, foremen and kindred workers, and a smaller increase in sales and service workers. There is a great decrease in operatives and kindred workers and laborers."⁸

The Social Structure of Bridgeport

There are distinct features of the social structure of Bridgeport which deserve to be highlighted. The first of those is an unusual ethnic complexity. Bridgeport has what is unquestionably the most diverse ethnic make-up of any city in Connecticut.⁹ This degree of cultural complexity, while bringing a great richness to the city, is also likely to be a factor in impeding community organization across ethnic lines. Thus, it is possible that the population sub-groups of Bridgeport might tend to be fairly insulated from one another and hard to organize as a pressure group.

Another feature of the social structure which is important is the industrial nature of the city. Bridgeport is a manufacturing town. It produces many items, from airplanes and brake shoes to girdles and electrical components. Corollaries of an industrial city are also present: there is a constant influx of new waves of immigrants, and it is a union town.

This industrial pattern also implies a division within the greater Bridgeport community between the recently migrated or ethnically separate, unionized workers of the central city and the white, native managers, white collar workers, owners of industry and professionals who tend to reside in the surrounding suburbs. The new minorities and the workers remain in the central city while the old minorities, the managers, and the businessmen have migrated to or settled initially in the suburbs around Bridgeport.

7 Greater Bridgeport Regional Planning Agency, Trumbull, Conn. August 1962, p. 59.

8 Ibid., p. 57.

9 Facilities for the Retarded, 1965 Connecticut State Plan.

The socio-economic and geographical divisions of the region imply distinctions between the ethnic, urban working groups and the native-managerial-suburban middle and upper groups. The core city is characterized by a population which has not totally assimilated, which is working class, often on or near the margins of poverty, which may be problem ridden, and which is unlikely to be easily mobilized in the quest for problem solutions. The suburbs, in contrast, increasingly house the residences of the educated, activist, middle and upper income groups, who often seek solutions.

It is in this context that the Parents and Friends of Mentally Retarded of Bridgeport and the Project may be viewed. Many voluntary associations can be characterized primarily as solution-seeking and action-oriented groups. They represent segments of a population whose income and educational level place them above the general population of the inner city. These are interested, articulate, informed individuals. They are an activist elite.

In the case of the mentally retarded in Bridgeport, the locus of privately initiated action may well be in the suburban middle and upper income groups, although a wide range of population elements participated. This pattern is both beneficial and restrictive. It is beneficial in that the organizers and activists are articulate and knowledgeable in their efforts to marshal pressures for the pursuit of change. They have the necessary organizational abilities and the necessary "contacts".

What must be determined, however, is whether such a group can truly represent the panorama of needs and desires of an entire community, especially as those needs relate to mental retardation. An association of action-oriented individuals may seek out the kinds of services which parents of retardates deem proper. These services fit into a way of life in which money for medical care may be available, in which travel and vacations are possibilities, and in which women are likely to seek careers. Thus, such groups may seek the need for private diagnostic and treatment facilities, for short-term residential units, and for day care centers.

The poorer population segments, on the other hand, are in greater need of public facilities, parent education programs, and, perhaps, family counseling. The question arises as to whether the needs of this poorer segment of the Bridgeport population, which are under-represented among action groups just as they are typically under-represented in most voluntary community organizations, are articulated in any area which is likely to recognize and to provide their needs with an adequate airing.

The point to be derived from this is that the operation of an organization cannot be understood without reference to the community environment. While some might suggest, perhaps as criticism, that the Parents and Friends of the Mentally Retarded of Bridgeport, Inc., is an upper-middle class organization which is attempting to secure the kinds of services desired by an upper-middle class population, this would represent a narrow and incomplete perspective. Rather, it must be asserted that the Parents and Friends organization is an accurate representation of the social structure of the greater Bridgeport community and of the patterns of voluntary associating found in many organizations in similar communities. Its members and leaders have been drawn from various population elements, from suburbs and

city, from professionals and workers, from self-employed, and privately as well as publicly employed. Some underrepresentation of recently migrated groups and the new ethnic minorities does seem apparent. Given this, one can understand and perhaps predict some of the projects and interests of such a group.

One can also understand some of the areas of action which were ignored or entered upon only half-heartedly or with limited effectiveness by the organization. Its successes may reflect the strengths of the community. Its inadequacies of its failures may in turn reflect the weaknesses and divisions of the community as a whole.

CHAPTER III

MACROSCOPIC AND MICROSCOPIC SUMMARIES OF THE PROJECT PROPOSAL

The Proposal statement dated October 1963, contained an introductory page, forty-nine pages of prose, charts, graphs, and tables and three appendices (entitled Justification of Specific Aims. The New Kennedy Center Building, and Existing Relationships with Other Community and State Agencies and Other Resources.)

The introduction contained the statement that

The President's panel report outlines a national program of the prevention of retardation and the development of a program of comprehensive services to make possible happier and more productive lives for the nation's five and one-half million retarded citizens.

Two key ideas followed in the introduction. Both reflected the special significance for the national effort attributed by the Association to the Project which was being proposed.

No other American city has greater readiness for accepting and meeting the challenge of a national program for the retarded than Bridgeport, Connecticut. It has a wide range of services, a sound basic philosophy of programming and an unusual community acceptance of the retarded.

The request for a Demonstration Project Grant from the Vocational Rehabilitation Administration for a period of five years for the development of comprehensive community-based services is a means of implementing the National Program. We are most confident that the granting of this request will provide Bridgeport with the opportunity of serving the nation.

At a macroscopic level, the Project was calculated to

...develop a model or plan of (a) comprehensive services based upon the resources of the (b) community and to show that the development of such community-based services is the logical and most effective way of achieving a (c) "Spectrum of Opportunity" for the retarded individual. An immediate effect will be a vastly greater range of (d) vocational goals and aspirations for the retarded.

The Proposal went on to describe the project as "...a venture into the relatively new field of community organization for the retarded" and from this premise went on further to state that "...the concept of a model of comprehensive community-based services must be considered as a working hypothesis. The procedure required in establishing the model or plan as a practical service will evolve as a part of the active ongoing project."

The Proposal then enumerated five "basic principles" that "guide the specific aims [and] may be stated at the outset." These "principles" were expressed as follows:

1. A model of comprehensive services for the retarded requires the commitment of the total available resources of the society, including its monies, agencies and manpower, (at local, state and national levels.)
2. The model of comprehensive services should be soundly based upon the normal operations of the community and not isolated in a separate "community" or institution.
3. The idea of a 'spectrum of opportunity' for individual retardates must be a natural outcome of comprehensive services based within the community which is available to all others. Its effective functioning depends upon the proper use and coordination of these services in a time sequence which can best serve the individual.
4. The 'spectrum of opportunity' will be reflected in a greater range of vocational goals and aspirations.
5. The sociology of the project itself, or the dimension of the process and techniques, is vital to the effective demonstration of the comprehensive model and future application to other communities and to other groups of handicapped

These five "principles" were presented as orientational in function, that is, as providing the frameworks for specific aims of the Project. Five specific aims were outlined, each sub-headed, as follows:

a) Specific Aims Related to Comprehensive Services

1. To promote effective working relationships between local, state, and national agencies and to examine the role of each in a comprehensive approach.
2. To demonstrate the effective use of local and state planning as resources in the planning of comprehensive services.

3. To determine and demonstrate the ways by which citizen participation and action at the city or town and state level, effect the building of a comprehensive model of services to the retarded.
4. To demonstrate that the component services of a model of comprehensive services for the retarded includes existing community facilities not now serving the mentally retarded.
5. To demonstrate the ways in which good concepts in programming, which have proven successful in other communities, are adapted for Bridgeport as part of the comprehensive service program.
6. To demonstrate the program areas for effective use of skilled and trained volunteers in a program of comprehensive services.

b) Specific Aims Related to Community-based Programs

1. To define the needs of families of the mentally retarded and to transpose these into services making maximum use of the family structure as part of the training process.
2. To demonstrate the ways in which communication, cooperation and coordination between professional disciplines and volunteer groups can be increased for maximum use of all community resources in developing services to the families of the retarded.
3. To determine and demonstrate the role of the local Association for Retarded Children in a local comprehensive service.
4. To demonstrate the effective use and relationship of local universities to a model of comprehensive services.
5. To demonstrate the techniques by which cities and towns plan and work together in the development of comprehensive services within a metropolitan area.

c) Specific Aims Related to "Spectrum of Opportunity"

- i. To define the variety of needs of individual retardates and to design the services to meet their needs and maximize their vocational potential.
2. To demonstrate the methods for initiating and carrying out training programs to meet the particular needs of the individual retardate in the proper sequence and at the proper time.

d) Specific Aims Related to Vocational Goals

- 1. To develop a basic regional plan for integrating and for handling community needs in the vocational area.**
- 2. To define the variety of adult and vocational services for the mentally retarded within a framework of comprehensive community-based services.**
- 3. To demonstrate effectiveness of a basic vocational evaluation and training unit as a method of determining vocational service needs and creating community vocational services.**

e) Specific Aims Related to Process and Techniques

- 1. To demonstrate the role of a Project Staff in the planning, determination of needs, and implementation of a comprehensive program within the framework of a community agency with an existing staff and program.**
- 2. To demonstrate the process for arriving at a model of comprehensive services which will be consistent with the regional planning for the selected area and will coordinate with the projected development of the area in terms of anticipated growth.**
- 3. To demonstrate the technology for a built-in evaluation unit to capitalize upon the effectiveness of the programs and the wealth of generated data for both research and practical needs.**
- 4. To demonstrate the vital role of public relations, community relations and public education in the development of community services.**
- 5. To demonstrate the effectiveness of the joint efforts of volunteer laymen and professional workers in planning and implementing a comprehensive model of services.**
- 6. To demonstrate that the implication of comprehensive community services is, in effect, a form of prevention incorporating medical, behavioral and social resources.**

The significance of these specific aims for the particular community of Bridgeport, Connecticut, was re-stated in the Proposal's later pages as follows:

The purpose of the Bridgeport project is to develop a model of the entire "spectrum of opportunities" for the retarded. We believe that de-

velopment of this model will lead to a great increase in the level of aspirations of the retarded and their families; to a substantial widening of their educational, vocational and social horizons; to better adjustment to their homes, jobs and families; and to a greater degree of self-fulfillment and happiness than the retarded have ever known. (pp. 9-10)

Bridgeport's project was stated to be a demonstration of community-based services. The "documentation" of a sub-aim "e" above "should become an important part of the methodology for future planning in other communities."

The Proposal contained other emphases on the Project's inclusion of demonstration and research as part of its overall aims. The Project was classified by the applicant in the Proposal as a demonstration or model of services, and the point was made that "research [*italics in original*]" will be necessary to give an operational definition of the model."

The Proposal for the project moved to a microscopic level when the prose turned to "methodology" and "implementation", beginning on page 18. This was presented as a series of "hypotheses", which can be paraphrased as follows: (1) A comprehensive model of services requires the commitment of the "total resources" of the community: monies, agencies and manpower; (2) A strong organized and coordinated state level program is a condition for comprehensive services; (3) "core" and "branch" services are necessary in a metropolitan area; (4) A "key agency" is required for comprehensive services, as a catalyst, guide, locus for the demonstration of new ideas, focal point for information and referral as well as consultation, and as a source of procedures to move retarded individuals along the "spectrum of opportunity"; and (5) temporal phasing of services among public and private agencies permits the "key agency" to shift efforts and resources to "new and promising service areas."

These ample words were not supplemented in the pages of the Proposal by any statements about the community of Bridgeport, the scope of opportunities that existed there for the retarded, and the nature of any barriers to advancement, achievement, or equality.

Thus, the five specific sub-points were presented fundamentally as idealizations of change that could be introduced in virtually any community. This was not so stated, but absence of detailed references to the social organization of Bridgeport requires such an interpretation.

This section of the Proposal contained a variety of subsidiary points which are extremely important. These included (1) the statement that the Kennedy Center in Bridgeport has "traditionally functioned" as the "key agency" and "...already provides a great number of component parts of the model;" (2) the prediction that the "new Kennedy Center building will provide the physical space for demonstrating new program ideas;" (3) the plan to introduce "a systematic record keeping procedure ...to follow individual retardates along the continuum as well as maintaining a history of developing relationships between community agencies;" (4) the forecast that "a systematic and coherent approach through a key agency of this kind will channel the already dynamic efforts of volunteer and professional workers into a more profitable deployment of energy..." and (5) the anticipation that growth of services will require the increasing

participation of both public and private agencies.

The agenda outlined above tied the terms of "model" and "comprehensive services" in with the existing Kennedy Center and the programs to be situated in the building then under construction. This was a stabilizing point, in the sense that a new set of eventualities was linked with an existing organization and its activities, within an already-planned physical plant.

Change was described as the "growth of services within the model" (21). Significantly, the prose here did not as such refer to the "community", but rather referred to public and private agencies or organizations whose increasing participation was said to be a precondition for the growth of services. Thus, the implicit role sketched out for the "key agency" was as a broker or catalyst that would encourage, entice, facilitate, and in various ways increase the engagement of public and private agencies in services for the retarded and their families.

"Opportunities for growth" dependent on this increase in agency participation were enumerated. The conceptions held by the Proposal writers in 1963 concerning the areas where such opportunities for growth existed, where some changes could be anticipated, appeared as significant highlights of the initial agenda of the Project. They were as follows:

- (1) the increasing of clinical, day care and vocational services by means of presumed increases in the grant-in-aid program of the state's Office of Mental Retardation;
- (2) the development or increase of programs in the public schools dealing with pre-school and school level vocational training and workshop areas. Recreation was also identified as an area of responsibility for public education;
- (3) the inclusion of the mentally retarded in the scope of services provided to the community's population by other local and private agencies. Illustrations provided were the Visiting Nurse Association, Family Services Agencies, YMCA's and YWCA's, Homemaker Service, Child Guidance Clinic, and "etc.";
- (4) the further inclusion of the retarded in the then present vocational services in the community, such as the Goodwill Industries and the Bridgeport Sheltered Workshops organization; and
- (5) the establishment of a Bridgeport Area Regional Center "... to provide residential care within the community." It was stated that authorization was anticipated for the 1965 session of the state legislature.

The Proposal listed various goals and objectives for the Project, and these were presented at diverse points throughout. Redundant elaborations of these lists were included in the narrative. References, often repeated were made to "model", "comprehensive services", "spectrum of opportunity", "key agency", "relationships", and "growth of model". These terms occurred very often throughout the narrative, although criteria for their partial or full attainment elude the reader of the Proposal.

One fairly specific list of objectives was presented as deriving from the "statement of goals of the National Association for Retarded Children", and is as follows:

- (1) Community diagnostic-treatment clinics with professional counseling for parents;
- (2) Home counselors to help parents in training the infant and child in the home;
- (3) Nursery classes, with normal children whenever possible; special nursery classes and day-care centers for the more severely retarded;
- (4) Special education with improved vocational training for the "educable" child;
- (5) Special education with improved social training for the "trainable" child;
- (6) Vocational training centers and sheltered workshops, including personal adjustment training and terminal employment opportunities;
- (7) Community centers with recreational, social, and counseling facilities for the adolescent and adult retarded who are dependent and cannot be integrated into the facilities for normal people;
- (8) Integration of the "marginally independent" retarded in society, including vocational rehabilitation and selective placement in regular employment;
- (9) Dynamic, community residence centers;
- (10) Research and professional training.

This was immediately followed by what the writers of the Proposal describe as "other obvious needs within the community." This list follows:

- Short stay facilities for family crises and to allow parents to have vacations and meet personal obligations.

- Half-way houses to give former residents of institutions a means of reintegrating in the community and provide supervised after-work life for retarded people who can be employed in the community.
- Guardianship plans and legal assistance for parents whose anxiety about their children after the parents die is a persistent problem.
- Services and activities for adult and aged retarded persons.
- Re-evaluation of the criminal responsibilities of defective delinquents, and a study of the best means of helping and caring for such individuals.
- Help in the choice and administration of drug therapy for those individuals who need it.
- Special help with dental problems, such as with those individuals who must have dentistry performed under total anesthesia.
- Corrective measures for improving speech, hearing and sight defects.

One looks in vain, however, for a clear indication of the relationship between these specific "objectives" and "needs", on the one hand, and, on the other, such broad concepts as "model", "comprehensive services", "spectrum of opportunity", and "growth of model". Whether attainment of all or some, and if so how many, of the ten points enumerated by the NARC, or of the eight "other obvious needs", would be necessary to satisfy the commitments implied in the broad concepts, was left unstated.

A more focused and detailed schedule of changes and of efforts anticipated for the Project was presented later in a most useful form. First, it formulated a time table for staffing, program and services development. Second, it outlined which developments were anticipated in each of the various groups or agencies active in retardation services in Bridgeport.

These formulations were preceded by a statement that:

Throughout the five years of the project, basic emphasis will be maintained upon the growth of the comprehensive model and the relationships between the component parts. However, there will be a changing and flexible program within the "key service".

The detailed schedule was given in the Proposal in time table form as follows:

The first two years of the program will be devoted to staff development to make available the necessary personnel to carry on inter-agency relationships; the organization and staffing of planning and study committees; the creation of new services at local and state level; volunteer and professional training seminars and workshops; establishing procedures for the spectrum of opportunity; development of the "core" and "branch service" approach; upgrading present services; initiation of a comprehensive program in public education and community relations and developing evaluation and process procedures and techniques.

The third year of the project will see the continuation of the growth in the variety of services with a retesting of evaluation and process procedures.

The fourth year will emphasize community agency participation with decreasing program emphasis in Kennedy Center. This same year should begin the working out of roles and relationships with the "regional center" established in Bridgeport by the State Office of Mental Retardation.

The final year will emphasize the evolving of a specific role for the "key service" within the comprehensive model and special emphasis and concentration on the development of techniques for application to other communities. (pp. 22-23)

Detailed attention was given to the "basic methodology" for the Project. Nine pages of the forty-nine page document covered this "basic methodology", which is stated as "necessary for evaluating the effect of the project on the community." It was further stated that

In order to measure the effectiveness of the project a number of major control groups will be necessary. Without a comparison of this kind, it would be impossible to determine the nature of the model or its impact on the community. The major control groups will follow three forms: first, matched control towns for the town of Bridgeport; secondly, matched institution or service; and thirdly, a community or service acting as its own control. [*italics in original*]

Comparisons with New Haven and Hartford were projected. Detailed studies were planned, requiring the collection of data dealing with the different ways that particular

services would be provided in these cities. This would include comparisons of referrals to and from state institutions, clinics, and vocational rehabilitation agencies. A ten year span for these projects was anticipated, particularly to determine effectiveness of services by longitudinal follow-up of cases.

It was further stated that this basic methodology would be applied to each of the "specific aims of the project, comprehensive services, community-based 'spectrum of opportunity', vocational goals and aspirations, and the process dimension, and can be applied in turn to each of the townships within the Greater Bridgeport area."

These, then, are the purposes and methods presented in a document in 1963 to the federal government as the basis for a requested grant of money. An award was made, and five years of activity have ensued.

The Project Proposal in Detail

The Proposal is, as is apparent from the above, a large and detailed document that contains throughout lists of sub-proposals felt to be of major importance in the development of a comprehensive program of services for the retarded. Some sub-proposals suggest specific services for the retarded. Others are concerned with involving the community, preparing staff and other individuals to intensify the efforts of agencies with existing services, and generating interest and subsequent participation of agencies as yet not providing services for the retarded. These sub-proposals also cover the effort to bring information from other communities into Bridgeport and to feed to outside communities the benefits of experiences in the city. Frequent references are made to research in the form of testing or evaluating the demonstration as a whole and in specific parts.

A succinct summary is difficult because so many ideas are presented at scattered points throughout the Proposal. Some are fully discussed; others are mentioned in a very cursory fashion. We have presented above, in the Macroscopic and Microscopic Summary an outline of the Proposal as written, following its basic organization. Now, we present a re-casting of the Proposal document by means of a simple listing of these features of its prose that refer to specifically mentioned undertakings scheduled to occur at various stages of the demonstration. The Proposal contains, throughout its introduction and forty-nine pages of narrative plus sixteen appendix pages, a great number of proposed efforts and anticipated achievements in which the Project as a whole would invest all or some of its energies.

In effect, the Project set out at its inception a long list of specific events which were (1) identified as important and desirable, (2) realizeable during its existence and (3) attainable through its efforts.

The list below (Table 1) contains the detailed features of change which were to be pursued during the Project's span. It is an ample agenda for change, creation, and enhancement.

TABLE 1: LIST OF SPECIFIC SUB-PROJECTS IN 1963 PROPOSAL

Create greater citizen participation.

Recruit and train volunteers.

Enhance communication, cooperation and coordination between professional disciplines and volunteer groups.

Demonstrate the role of the local Association.

Make effective use of local universities.

Develop techniques by which cities and towns plan and work together.

Develop a basic regional plan.

Define the variety of adult and vocational services for the M.R.

Demonstrate the effectiveness of a basic vocational evaluation and training unit for determining vocational service needs and creating community vocational services.

Demonstrate the role of a "project staff".

Demonstrate the vital role of public relations, community relations and public education.

Demonstrate the effectiveness of the joint efforts of volunteer laymen and professional workers in planning and implementing a comprehensive model of services.

Plan reorganization and extension of existing facilities.

Establish community diagnostic-treatment clinics.

Provide professional counseling for parents.

Provide home counselors.

Develop nursery classes (with normal children when possible).

Extend special nursery classes.

Expand day care centers for the severely retarded.

Provide special educators with improved vocational training for the educable.

Provide special educators with improved social training for the trainable.

Establish vocational training centers and sheltered workshops including personal adjustment training and terminal employment opportunities.

Facilitate the integration of the "marginally independent" retarded in society, including vocational rehabilitation and selective placement in regular employment.

Establish dynamic community residence centers, short stay facilities and (half-way houses).

Initiate research and professional training.

Develop guardianship plans and legal assistance programs.

Improve services and activities for adult and aged retarded persons.

Re-evaluate criminal responsibilities of defective delinquents, and study the best means of helping and caring for such individuals.

Help in the choice and administration of drug therapy for those individuals who need it.

Provide special help with dental problems.

Provide corrective measures for improving speech, hearing, sight defects.

Involve public health nurses in retardation services.

Strengthen the state association (CARC).

Establish an information and referral service.

Encourage development of pre-school classes.

Expand recreational programs.

Initiate and operate a systematic record keeping procedure to follow individual retardates along the continuum as well as maintaining a history of developing relationships between community agencies.

Involvement in a comprehensive services plan of the following agencies: Family Service Agencies, Y.M.C.A., Y.W.C.A., Child Guidance Clinic, Homemaker Service, Goodwill Industries, Bridgeport Sheltered Workshops.

Enhance inter-agency relationships.

Organize volunteer and professional training seminars and workshops.

Establish community centers with recreational, social and counseling facilities for the adolescent and retarded adult.

Prepare a director of services.

Develop informational "kit".

Organize community and professional lecture series concerning retardation to be sponsored with local universities and agencies.

Organize leadership training workshops for volunteers.

Furnish visiting services to other communities.

Provide consultation services in:

- Recreation
- Community Organization
- Vocational counseling
- Research

Provide comprehensive publicity and public education in all mass media.

Develop brochures and bulletins for communication.

Conduct attitude surveys on mental retardation.

Structure and develop day care services in outlying communities and relate day care services with other community agencies such as hospitals and home care programs.

Provide director of adult services, social worker, clinic director, service specialist, part-time community relations specialist.

Establish procedures for foster home care through public welfare and child caring agencies.

Establish a "Career Opportunities Program" for recruitment of retardation professionals.

Establish K.C. as professional training center for social science disciplines by opening student training, research and field work relationships with professional schools.

Establish major control groups for evaluation of demonstration project.

Conduct research on state institutions referrals to the community for rehabilitation.

Encourage inclusion of retarded in hospital services, covering early identification and counseling.

Establish parent education and counseling programs to be established with family service and child care agencies.

Conduct research on cases passing through the three clinics over a ten year period.

Arrange for and utilize pilot studies by Bridgeport Public Schools; New Haven Community Progress, Inc.; Bridgeport Hospital; and Southbury Training School.

Conduct attitude surveys among parents of retarded in community residence.

Conduct surveys dealing with operations of diagnostic clinic, social agencies and the Project staff.

Utilize research by Fairfield University Sociology Department on work aspirations among the Puerto Rican population.

Utilize findings of Project REACH on school drop-outs.

Conduct research on interactions between community and Project, between Project and agencies, and between professionals and lay volunteers.

Maintain utilization of the following agencies or (individuals) evaluating effectiveness of the Project

- Office of Mental Retardation
- State Office of Education
- Southbury Training School
- Superintendent of Schools and School Board Members
- Community Progress, Inc., New Haven
- Bridgeport School Psychologist
- United Fund and Community Council
- University of Connecticut School of Social Work
- Fairfield University Sociology Department
- Fairfield University Psychology Department

Develop and continue cooperative relations

Conduct research comparing cases served by the diagnostic clinics in Bridgeport, Hartford and New Haven.
Conduct research of cases referred during a ten year period to the state institutions from the three cities (including the five years of the project).

with:

Office of Mental Retardation
University of Bridgeport School of
Nursing & Secretarial Division
Southern Connecticut State College
Special Education Division
Southbury Training School
State Welfare Department
Bureau of Vocational Rehabilitation
State Park & Forest Commission
State Department of Health
Bridgeport Hospital
St. Vincent's Hospital
City of Bridgeport Division of Human
Affairs
Crippled Children's Workshop
Cerebral Palsy Center
Bridgeport Speech and Hearing Clinic
Bridgeport Volunteer Bureau

Facilitate practical implementation of research findings by organizing research as part of comprehensive community services model.

CHAPTER IV

METHODOLOGY OF THE PROJECT WRITING STAFF

This monograph needs to be understood in several lights. First, it is a report about a five year demonstration project concerned with the enhancement of services and opportunities for the mentally retarded in a single community. Second, it is a report written by a Project Writing Staff especially recruited to provide a detailed and objective appraisal of the changes that occurred and the events associated with them. And, third, it is a report of the Association that received the grant of public funds from the federal government.¹

A staff was recruited by the Project Writer to assist in the interviewing, observation, analysis of materials and writing essential for the preparation of the monographs and the Final Report.

The members of the Project Writing Staff and their experience and qualifications are as follows:

(1) Louis H. Orzack, Ph.D.

Professor of Sociology, Rutgers University, and Chairman, Department of Sociology, Newark College of Arts and Sciences; former Research Grantee, National Association for Retarded Children; former Assistant Director, Division of Mental Retardation, Massachusetts Department of Mental Health; former member, Massachusetts Mental Retardation Planning Board.

(2) John T. Cassell, Ph.D.

Professor of Special Education, St. Joseph College, West Hartford, Connecticut; Director, Gengras Center for Exceptional Children; Secretary-Treasurer of the American Association on Mental Deficiency; Member, Board of Directors, Greater Hartford Association for Retarded Children; Member, Board of Directors, Greater Hartford Cerebral Palsy Association.

¹ The Association is submitting this report to the actual granting agency, Social and Rehabilitation Services of the U. S. Department of Health, Education and Welfare, in discharge of its obligations to furnish a final report of what was accomplished through the expenditures of the funds received.

(3) Harry Halliday, M.Ed.

Senior Supervisor, Rutland Heights Rehabilitation Center, Rutland, Massachusetts; former Mental Health Coordinator, Division of Mental Retardation, Massachusetts Department of Mental Health; former Instructional Supervisor Owatonna State School, Owatonna, Minnesota; former Special Class Teacher and Coordinator of Vocational Training, Mansfield Training School, Mansfield, Connecticut; former Chairman of Section on Vocational Rehabilitation, Northeast Region, American Association on Mental Deficiency.

(4) Benoit Charland, M.Ed.

Senior Supervisor, Bureau of Special Education, Massachusetts Department of Education; former Principal, Hathorne State School, Danvers, Massachusetts; former Executive Director, United Cerebral Palsy Association of Greater Fall River, Massachusetts; former Assistant Director, Hospital Improvement Program, Paul A. Dever State School for the Retarded, Taunton, Massachusetts; former Special Education Teacher.

(5) Jeffrey Salloway, Ph.D.

Assistant Professor of Sociology, University of Wisconsin-Milwaukee.

Marver Schreiber, M. S. W., Associate Professor, School of Social Service, Fordham University, and Melvin E. Cohen, Ed. D. Regional Mental Retardation Administrator, Massachusetts Department of Mental Health, served as special consultants during various phases of the preparation of the monographs and the final report.

Mrs. Marcia Fleischman served as typist and secretary for the Project Writing Staff. Mrs. Ann Buxbaum provided editorial help with the final manuscript.

This Project Writing Staff began work in late Spring 1968, under the supervision of the Project Writer. Several members participated in an intensive two week field visit to Bridgeport during June 1968.

During that time, a central "headquarters" was maintained at the Association's offices in Bridgeport where materials and files were collated, read, and discussed, and where summaries of certain sections of this physical record of the Project's efforts were prepared. Various staff members read and commented on the Project proposal and subsequent progress reports.

Interviews were held with members of the Association's staff at its offices and at its outlying service or program offices. Visits were made to the State Regional Center and interviews held with some of its staff members. The various program centers of the association, key community agencies, and various public facilities, such as the schools, community action agencies, and the Division of Vocational Rehabilitation were visited and interviews conducted there.

Contracts were made and interviews were conducted during those two weeks, and during the months that followed, with many individuals, including present and past staff members of the Project, former Project Directors and numerous service personnel.

Interviews and discussions with members of the Association's Board of Directors were held. On one occasion during June 1968, members of the Project Writing Staff met with members of the Board. The Project Writer met on other occasions with the Board as a unit and with individual Board members, both present and past.

Discussions were held with officials of various state and local agencies in Bridgeport and in Hartford, as well as with officials of the Connecticut Association for Retarded Children.

Throughout their work, the Project Writer and the Writing Staff maintained an open-minded but concerned perspective, following the general theme of "telling it like it is." The approach was based on the idea that an outsider to the community, to the Association, and to the Project, could best review the many events and complicated processes involved in its genesis and evolution. His background in the behavioral science of sociology, and previous activities in the area of mental retardation research and administration, were described as relevant qualifications for his selection as Project Writer.

The role delineated for the Project Writer was to prepare the final report for the five year demonstration project, as well as a series of monographs to describe areas where achievements had occurred.² This included also the stipulation that, as writer and author of the monographs, he would collect and analyze the information and data necessary, and as the author, would make the final decision on what would be included in the various manuscripts. Agreed also was that the Board of Directors or Project Committee of the Parents and Friends (Kennedy Center) would read the manuscripts in draft form and make suggestions concerning factual details and interpretations. Any suggestions thus made, if deemed advisable by the author, would be included in the final manuscript. It was further agreed that the Board would write any necessary letter of transmittal, or introduction or addendum to the report and monographs. The Kennedy Center would publish the report and monographs and a mutually acceptable printing method would be agreed to by the Project Writer and the Project Coordinator (the association's Executive Director).

² The resulting Monograph Series on the Pursuit of Change includes the following titles, in addition to the current monograph: 1. "Day Camping and Leisure Time Recreation Activities for the Mentally Retarded"; 2. "Experiences of Former Special Class Students and An Educational Work/Experience Program for Secondary School Educable Mentally Retarded Children"; 3. "Residential Programming and Residential Centers: The Experience in Bridgeport"; 4. "The Evolution of a Sheltered Workshop for the Retarded: The Idea and the Process of Implementation"; 5. "Administrative and Sociological Factors in Organizing Change: Toward New Services for the Retarded"; and 6. "Processes of Change: Goals, Obstacles and Results in Generating New Services for the Retarded."

The net effect of this was to provide a rare and very useful opportunity for a detailed analysis of the interaction between an on-going set of systems in a community and an effort to bring about change in their structure and function. Social change is a standard topic in sociology, organizational change a major category of theoretical importance for those concerned with the analysis of large-scale formal organizations, and community change a topic of continuing interest. The interrelationships between beliefs and action, dissent and consensus, community authority and participation outside intervention and community control, are of vital social importance.

This analysis also could be very useful to the Association that received the grant, by demonstrating the impact of the intensification of efforts to involve the community in broad-based services for the retarded. The recruitment of an outside group of specialists familiar with retardation services and acquainted with methods for the analysis both of those services and of change in organizations and in the community would make possible an objective view.

The end result would be careful and systematic observation, analysis, and interpretation of (1) the relevant status quo at or before the beginning of the change project, (2) the plans for change, (3) the process of change itself, including the construction of a Project model and its staffing, the kinds of efforts undertaken, and the record of achievements, of problems, or of failures, and (4) the net changes in the status quo that may be attributed to the change project.³

The nature of this report, then reflects the fact that an outside behavioral scientist is the author responsible for the interpretation and for the collection of the necessary materials gathered by himself and his staff.

It also reflects the fact that the Writing Staff did not participate in any of the events and processes occurring during the Project. Reliance had to be placed on contemporary records and the statements of participants in, or observers of, events. Some records of events were available in the Association's offices; others were supplied by formerly active members or employees of the association and its Project, or by persons associated with various community and governmental organizations whose areas of responsibility touched upon the activities of the Project and of the sponsoring association.

³ The approach follows the model provided in such sources as: Martin Rein and S. M. Miller, "The Demonstration Project As A Strategy for Change", pp. 160-191, in Mayer N. Zald, Editor, Organizing for Community Welfare (Chicago: Quadrangle Books, 1967); E. A. Suchman, Chapter 3, "A Model for Research and Evaluation on Rehabilitation", pp. 52-70, in Marvin B. Sussman, Editor, Sociology and Rehabilitation (Washington: American Sociological Association, 1966). For a different approach, see Jerald Hoge and Michael Aiken, "Program Change and Other Organizational Properties: A Comparative Analysis", American Journal of Sociology, 72, March 1967, pp. 503-520.

The extensive turnover of Project staff; the fact that the bulk of the history of the Project included two tumultuous eras of dominance by two powerful Directors, and a third era of a more quiescent character toward the end of the Project's life; the organizational changes in both the Project and the Association; the occurrences of crises and turning points; and the introduction of new government sponsored and government operated centers of activity in the field of service related to that of the association: all these complicate the environment we have studied and described in this report.

These have complicated our methods as well, particularly in two respects. The first is the varied character of the written records that were made available to us and that we sought out. Housecleanings of office files, letters and correspondence, memoranda, and records occur in all organizations, and the Association was no exception. Materials critical for the reconstruction of past events were sometimes temporarily or permanently unavailable. Changes in filing procedures often result in the mislaying or discarding of items. When persons leave any organization, they may screen their files, leaving certain materials, discarding others, and taking still others with them. When departments are terminated, offices shifted, or individuals leave, the remaining staff may not order or maintain the materials remaining in a systematic fashion.

It should be noted here that the current office and professional staff of the Association and the Project committee were extremely helpful and cooperative in supplying materials, hunting for files, turning up old records, and looking systematically for all items requested. In a number of instances, persons no longer connected with the association supplied materials from their personal files that were not to be found elsewhere. From these varied sources, we obtained a large quantity of written materials dealing with the events of the Project, but it cannot be said that the entire body of items we desired always reached us.

The second complication concerns the location and use of informants and their statements. The Project Writer met initially with the Board as a body and with the Project Committee; then with most of the members of the staff, he joined the Board at an evening meeting during June 1968. The Writer and various members of his staff joined in discussions on many occasions with the current Executive Director of the Association. The executive secretary of the Association provided many insights and interpretations about developments. These individuals have been available when asked and often volunteered information and materials useful or even critical to the preparation of the Report and the earlier monographs. Various individuals currently affiliated with the Association and the Project responded very openly to detailed questions about events in the past years of the Project. Their contributions have been invaluable.

Their recollections of previous events and interpretations of them have been complemented by a systematic set of interviews and discussions held with many persons not now affiliated with the Association, and with others who hold or have held responsible positions in organizations that have interacted with the Association or the Project. This included the contacting of a number of former staff members. Some had been dismissed from their positions. Some had resigned. Among all of these persons we found, not surprisingly, a range of feelings from substantially positive to substantially negative. In no instance was our request for an interview rejected.

Statements made by both past and present participants were checked and compared. Re-interviews occurred on a number of occasions in order to verify our conclusions about perspectives on events and situations and to clarify our understanding of the frequently diverse manner in which these events and situations were recalled or perceived.

Written statements were obtained from some individuals to amplify interview notes or when relocation at a distance prevented a personal interview. Leaders or executives of certain organizations or groups responded to similar requests for information.

As the Project Writing Staff reviewed the proposal for and the history of the Project, and sought to cope with extensive arrays of materials, records, minutes, letters, memoranda, reports, and interview notes, we found numerous instances of specialized sub-projects or sub-efforts of the Project, where materials available to us proved inadequate or insufficient as a basis for any reasoned judgment or interpretation. We learned in many instances by statements in the written record, or by hearsay in the recollection of informants, that something had been attempted on this or that sub-project. In many of these cases, the written records of the events as they initially occurred could not be found, and indeed, in many instances, the likelihood is that such written records did not ever exist. For a significant number of these, the close of the Project finds that no record of effort or achievement was ever written and no one still active in the community knows either their current status or precisely what happened in the past. Retrospection is often as good as contemporaneous monitoring, but sometimes not; in any event we had to rely extensively on people's statements about what had happened months or years before.

A cautionary point must be made. The Project Writing Staff was associated with the Project and its events for a period of a few months, on a part-time basis. Much more could have been accomplished had the Project maintained throughout its history a commitment to the systematic collection of materials on its actions, and to the preparation and completion of manuscripts and reports that would have been published throughout its life.

In the span of seven months, the Staff had to acquire an initial acquaintance with Bridgeport, the Association, retardation services, and the Project, to collate existing materials and search out more, to plan and conduct interviews and field visits, and, finally to draft a series of monographs and this final report.

Throughout our work, we were constantly aware of the interrelationship, dependence, and overlapping of sub-projects with each other. Attempts to isolate the history of specific sub-projects were often complicated by the fact that many sub-projects blended into each other in the recollections of informants, or evolved in intricate ways into new formats. Sharp delineations of specific key events of certain sub-projects could often not be obtained even with persistent and probing interviewing.

In reviewing the ideas set forth in the Project proposal, the Project Writing Staff attempted to evaluate each individual sub-project or change effort in terms of its current status, whether or not the specific sub-project was in fact specifically attempted and specifically fulfilled, and what part, if any, the Project as such played in whatever was accomplished. Our concern has been not only to elicit from the information available

that which was successful, but to identify and analyze the factors which hindered the accomplishment of the Project's goals.

The aim of the Project Writing Staff has been to conduct a "constructive evaluation" of the Project itself and its accomplishments. The underlying purpose has been to analyze the complicated history of the Project so that greater understanding of processes involved in an undertaking of this sort can be reached.

The Association has continued during the span of the overall Project, with a variety of activities of concern to its membership and Board. Certain of these activities have critically impinged on the Project or have been affected by the Project's efforts. The Association's concerns have been directed at improvements in the welfare of the mentally retarded in Bridgeport and have had an impact on the community.

Any expectation that complete success can ever be attained is misguided. If any criticism may be levelled at the Parents and Friends Association for attempting to improve provisions for the retarded, it must proceed from two fundamental points:

1. Mortal social beings and transient social agencies, which are involved in the effort to cope with and modify the environment of the community, are never completely successful either in bringing about change or even in agreeing on what changes are desirable.
2. This particularly complicated change effort had few models of successful change which could be followed as a pattern, and thus the innovating and pioneering efforts of the Association were breaking into territory that had not been explored by others.

This monograph will hopefully be useful to the members of the Association and its Board as a basis for knowing better what has happened in the past. The continuing effort to move further, both by the Association and by many other groups, may be influenced by such a report. It may also contribute to a better knowledge of the character of organizations than now exists in the behavioral sciences.

CHAPTER V

THE EARLY PURSUIT OF CHANGE

The Demonstration Grant (RD 1435-G) was awarded as reinforcement that would hopefully initiate new programs built upon previous achievements.

The Demonstration Grant (RD 1435-G) came to be seen by some in Bridgeport as acknowledgment for the past service programs that had been achieved and developed by the Parents and Friends Association. The grant could be seen as something awarded to the Association for past achievements and as funds that the Association could utilize to maintain its existing level of operations. For others, the grant could be seen as funds in anticipation of future programs and new types of operations to be developed.

The grant (RD 1435-G) was viewed in fact by many members and associates of the Association both as a reward for past efforts and as a mechanism that would permit the Association to continue, perhaps to expand, the operation of the current programs. This would primarily include the operational costs of various service programs covered by the "Kennedy Center" title.¹

Many key members and active proponents of the Project viewed it as a combination of reward for the past and of stimulation for the future. In effect, these represent different viewpoints. The first stresses the continuation and enrichment of existing programs for the retarded, primarily the same clientele that was already being served. The second stresses the necessity for innovation of new services and the inclusion within such services of more individuals drawn from throughout the community.²

¹ Heavy construction costs to be incurred in the erection of the new building on Virginia Avenue could thereby be met more easily by the Association itself.

² Which was the dominant view of members of the Association cannot now be determined, certainly not by any systematic polling process. However, some sources of information on this point do exist. One is the documents and written files both of the Association and of other groups. Another is the statements of individuals who are and have been associated with the Project and the sponsoring Association who have been available for interview.

The reward perspective would imply the extension of already established services and their focus on members of the Association and on dependents of members. The stimulation perspective would imply, in contrast, the development of new services and the initiation of efforts to encompass within their range a large number of individuals, not members of the Association, not currently serviced.

It appears that the approaches and perspectives of the first Project Director embodied innovation, extension, and change as well as the broad extension of current services to individuals not already being served. This provided occasions for conflict with various segments of the Association or its Board.

A complicating feature in the Association's pursuit of change concerns the wide variation of opinion that has existed over the years about the State of Connecticut's public services for the retarded, ranging from pride, through uncertainty to distress. Many of the active participants in the Association express a great deal of pride about the leadership that members of the Association have provided at various times while endeavoring in Hartford, the state capitol and seat of government, to formulate and direct statewide programs for the retarded. In the late 1950's, this took the form of active lobbying by members of the Parents and Friends of Bridgeport, both through and independent of the state Association, for legislation to benefit the retarded.

Once the legislation that established the state Office of Mental Retardation was passed with the help of such efforts by Bridgeport members, the involvement took other forms. One of the leaders in the efforts of the local Association during the 1950's and early 1960's became State Mental Retardation Planning Director and organized the project that led finally to the publication of MILES TO GO, its final report. Mrs. Evelyn Kennedy and Attorney Bernard Green, two key members of the Association's Board, have both served on the Governor's Advisory Council.

Frequent references are made by many of the active Board members of the Association to these important efforts of the Association and of its members in Hartford. Some take credit for pioneering in Bridgeport a program of services which they say provided a model for Connecticut's diversified system of regional centers for the retarded. This is, however, a matter about which some controversy exists. It is an undoubted fact that the state's Office of Mental Retardation was established in 1960 and that the regional center system began to be overtly planned and initially implemented shortly thereafter. Whether Bridgeport's Kennedy Center, with its diversified program of services, was actually a model for this is questionable.

It is noteworthy that the early formulations of the programs for the Association's building on Virginia Avenue,³ did not envision state operation of the facility. As one

³ The Building known as the Kennedy Center was constructed in 1963 and 1964 and operated from Summer 1964 to October 1965 by the Association. It was owned thereafter and operated by the state as the Bridgeport Regional Center. See Appendix III.

member expressed it,

"We did not envision state operation. The idea was to start off the building right with the [Project] grant and go ahead fast and furiously."

It does not appear from the record that the Association or its Board contemplated that, within a very few months of the opening festivities celebrating the operation of the building, there would be discussions with representatives of the state's Office of Mental Retardation about the necessity of state operation and acquisition of ownership. Financial difficulties confronting the Association because of higher-than-expected costs of construction and programs facilitated the transfer of ownership.

Even today, many key Association members express, in diverse ways, their regret about the state operation of the facility on Virginia Avenue. For some, it was a "state take-over." When they contemplate the possibility that other services still operated by the Association might conceivably be shifted in the future, through financial or programmatic necessity, to state operation, the "state take-over" of the one-time Kennedy Center building is recalled with extreme annoyance, and with a sense of great loss or failure.

The reaction to the state ownership also includes a lament for the exciting and youthful or exuberant period of the Association's achievements. "Those were exciting times, when we worked very hard, accomplished a lot. Those were the good old days. We used to have long meetings, and we fought the establishment of the city, the schools and the state, and we stood up for what we wanted." This fervent sentiment, often repeated in a variety of ways, reflect almost a classic nostalgia for youth. These recollections of these earlier years of growth and gains prior to state ownership of the building include references to long night meetings, cake sales, speaking engagements before various community groups, and exciting trips to legislative sessions in Hartford to appeal for more support.

A feature of the distress about the state is the dislike of institutional living at state operated Training Schools. Many of the members of the Association believe now and believed in the past that nothing much could be done to change these state institutions. One close observer of developments in the thinking of this and other parent associations states that the Association never tried to change the institutions in any direct sense. It did, he observes, make some indirect effort through legislation, but basically situated its programs for change in the newer regional centers outside the scope of the institutions. Keeping the retarded in the community where they would be included in existing programs meant keeping them out of the Training Schools.

Stages of Development of the Association

In the following material, we attempt an interpretation of the several stages of involvement by the Parents and Friends Association with community organizations and other groups that comprise important segments of the larger community. It should be kept in mind throughout that these stages are hypothetical and that they reflect the development of perspectives and vantage points of the Association and its membership, as we understand them with the advantages of hindsight. They reflect also the different reaches of the Asso-

ciation out to the community and the changes that occurred in the ways in which the Association attempted to influence and deal with those features of the community external to it.

This material must therefore be read with the detailed history of the Association in mind. We have therefore included separate historical accounts of the Association in the Appendix of this Report. These accounts were written by the Association staff at various times during the last ten years.

The first Appendix summary, written in 1960, three years prior to the Project presents the perspective of an active, achieving and imaginative group with a record of accomplishment and on the verge of new lands to conquer.

The second, third and fourth Appendix summaries were written in 1963 as part of the successful grant application to the federal government for the Project. It brings the history three years further ahead and justifies the proposal by recording the voluminous efforts of the Association and its goals for the Project.⁴

The fifth Appendix summary, written in 1966, reviews the internal problems of both Project and Association, and constituted the 1966 Progress Report of the Project to the U.S. Government.

The sixth Appendix summary, written in 1968 within the last months of the Project, was prepared as part of an application to the United Fund for additional monies, and reflects the financial needs confronting the Association in its efforts to continue on-going programs in the face of the termination of the five year Project, supported by grant RD 1435-G.

We turn now to the discussion of the stages mentioned.

Early Involvements With the Nation

A feature of the Parents and Friends of Mentally Retarded Children of Bridgeport, Inc., is that it is both (a) a local association of parents and others living in a single limited geographic area, concerned about the improvements of services for retarded persons in that area, and (b) an association that has had at different times involvements with other organizations that reach far beyond the confines of the city.

Eric Sandahl, a key figure in the Association particularly during the early years, served for some time during the 1950's as the editor of Children Limited, the newspaper of

⁴ The Project proposal is summarized above in Chapter 3.

the National Association for Retarded Children. He performed these duties from his home as a volunteer. In that role, he was in contact with the offices of the national association that led the parents movement throughout the United States on behalf of retarded during the 1950's and into the 1960's. Gunnar Dybwad, who served in those early years as the Executive Director of the National Association for Retarded Children and is considered a key leader in its efforts, worked closely at that time with Sandahl. Dybwad reports that:

In those years, Children Limited was by far the best source of information on mental retardation trends throughout the country. Eric Sandahl edited it single-handedly, and it was a volunteer job. He worked heroically at it....

Sandahl did the editorial work for Children Limited from his home in Bridgeport; he got reports from all over the United States. This accentuated the feeling in Bridgeport that they were a central point in the state and nationally.

This distinguished the Bridgeport Association from other local parent associations. It brought materials from throughout the country into the city, it made the Association a national clearing house where ideas could be screened, and it engaged the Association, through one of its most important members, in the efforts being undertaken across the country.

Mr. Sandahl had been a reporter and journalist. He was recently described as "verbal, imaginative, hard-working and informed." His job on the Bridgeport Herald brought him initially into contact with the Parents Association as did his own involvement as a parent of a handicapped child. His job in journalism is additionally significant, however, for the Bridgeport Herald which employed him at the time also served as the printing house for the NARC's Children Limited newspaper.

In an unusual fashion, therefore, the local Association was linked directly with the national association and with other state and local units throughout the United States.

These links withered in time, as editorship of the NARC paper went elsewhere, as the national office exercised more centralized initiative, and as other local and state groups forged ahead with their own programs or withdrew from significant interaction with outside agencies. Nevertheless, this early prominence and memory of that prominence linger as backdrops for the Association's later life. Some members are unaware of this. Others recall it with nostalgia.

Involvement With the State

The local Parents Association, as described earlier, was very active in the late 1950's in lobbying in Hartford for the passage of key legislation for the retarded. Members, such as Attorney Bernard Green, Mrs. Evelyn Kennedy, and Eric Sandahl, participated in this process. Both Green and Sandahl were very involved in drafting legislation. They and

others spoke throughout the state, in an effort to excite broad support for the proposals that had their backing and sanction. Significant legislation was passed during the period, providing state support for classes for trainable children, mandating participation by local school authorities.

The individuals mentioned were also significant in the establishment of the state-wide association, the Connecticut Association for Retarded Children, which actively supported and sponsored much new legislation.

Perhaps the most important change occurred in 1959, when the state's Office of Mental Retardation was brought into existence by the state legislature. Within the next two years, the Regional Center approach to service was initiated administratively by the OMR's establishment of such centers.⁵ Bridgeport was to become the site of a center in 1965, with state assumption of the title of ownership to the Association-built Kennedy Center.

Another important and unusual type of state leadership by the Association through a member of the Board, had occurred earlier. Bernard Green, a lawyer in Bridgeport, member of the local Association and now on its Board and also on the state's Advisory Council for Retardation, participated in the legal processing of an appeal by a mentally retarded petitioner to the United States Supreme Court for a reversal of his state court conviction on criminal charges. The petitioner in the case, Arthur Culombe versus State of Connecticut, 367 U. S. 563, sought reversal of a lower court conviction, on the grounds that a confession had been given under intimidation. Justice Frankfurter concluded for the Court that the retarded defendant with a mental age of 9 to 9-1/2 years was suggestible, his confession was not voluntary, and he had been deprived of his rights through violation of due process.

Mr. Green aided in the preparation of the brief submitted to the U. S. Supreme Court as a Friend of the Court by the Connecticut Association for Retarded Children. The case was very well known throughout the entire State of Connecticut. The events associated with the criminal acts had received very extensive notoriety through newspapers and other media. The brief submitted argued in effect that officers of the law used "devices" and techniques to persuade and coerce the petitioner. The brief condemned interrogators and authorities for their behavior during their initial contacts with the petitioner.

The event as a whole was one of the many efforts undertaken on behalf of the mentally retarded against the status quo pursued by the state Association and by a key member of the Board of its Bridgeport chapter. It is considered by those familiar with the history of the Bridgeport Association as a highlight of its early achievements.

⁵ See M. Michael I. Klaber, Chapter 13, "A Densely Populated Small State: Connecticut," in Part VI, Model Service Models, of Robert B. Kugel and Wolf Wolfensberger, Editors, Changing Patterns in Residential Services for the Mentally Retarded (Washington: President's Committee on Mental Retardation, 1969).

Involvement With State Planning

The Connecticut Mental Retardation Planning Project's striking publication, Miles to Go, published in March 1966, two and one-half years after the inception of the Bridgeport Project, concluded an effort of many citizens and groups throughout the state toward the planning of further improvements in the life of the retarded. Prepared under the auspices of the Office of Mental Retardation of the State Department of Health, and supported by a Mental Retardation Planning Grant awarded to that office by the Public Health Service of the U. S. Department of Health, Education and Welfare, the publication is an impressive compilation of statements about the past and present organization of services, and about directions for desired change.

The Parents and Friends Association played a part of some significance in the Planning Project. During its active existence, from July 1964 through December 1965, the Planning Director was Eric Sandahl. Mr. Sandahl had in a sense transferred the location of his activities on behalf of the retarded from Bridgeport to Hartford, and the area of his concern from the single city to the state as a whole. This has been described by some as a logical outcome of the step by step growth of strength of the Association in Bridgeport. This view, as expressed by an informant, is that, a new day having begun in Bridgeport, it was appropriate and desirable to call forth the same dawn throughout the state. "Bridgeport," recalled one active participant in the Association, "had shown that it could be done and Eric was going to get the state moving in the same direction."

In various other very critical ways, the Bridgeport Association was involved in the process of state-wide planning. Two members of the local Association were among the twenty-nine members of the Advisory Committee. Both were members of the state Mental Retardation Council, and one was Past-President of the state association. The task force on law was headed by the member of the local Association's Board who was its vice-president.⁶ Identified on the staff page was Mrs. Jeanne Sandahl, listed as Volunteer Writer. Mrs. Sandahl had been a Parent and Friend Board member.

A detailed analysis of the content of Miles to Go, to attribute or relate ideas and proposals to those undertaken by the Bridgeport association or its Project cannot be undertaken. The content of this extensive appraisal of the position and developmental trends of retardation services throughout the state is voluminous and covers many aspects of public and private services, the organization of those services, and what were considered to be the need for increased acceptance and more services. It is however necessary to summarize that report, at least in part. At several points, references occur in Miles to Go to the activities of the Parents and Friends Association and its Project.

⁶ He was also on the Advisory Council. The task force on residential care was headed by the Demonstration Project's Director. He was listed at the time of the publication of Miles to Go as "former director".

First, while there are various references to the local Association in Bridgeport and to the Kennedy Center, no reference can be found to the five-year Project or to the involvement of large federal funds in the efforts undertaken by the association from 1963 to the publication of the Report.

Second, two large fold-outs, the only two in the publication, present materials about the Association's activities. The first, appearing as double page 16, is headed "Community Resources in the Daily Life of the Retardate," and consists of a map of the section of Bridgeport where the Center building on Virginia Avenue is located. It depicts schools, churches, transportation routes, and actual and proposed residential facilities and homes. The second appears as double page 208 and presents the "contrast between facilities required for a private residential school and a community residential program." It emphasizes the desirability of home-like residences in established neighborhoods. The presented aim is for the retarded to participate in educational, recreational and medical facilities already present in the community. Special staff residences and a large institutional complex are deemed unnecessary. This material is attributed to a 1964 proposal by the Parents and Friends Association.⁷

The section on "The Regional Approach" (pp. 12ff) refers not at all in the text concerned with "Background of the 'Connecticut Plan'", to the Bridgeport community. References are made, for example on page 20, to "a close partnership ... between ... community agencies and the regional programs as they provide, among them, the full 'continuum of care' required by the retarded in the region." The regional centers at Seaside and New Haven are identified as "an outstanding example" and "the outstanding example" respectively (pp. 20, 21) of relationships first, between such a center and the public school and, second, of regional programming. The same section refers to Bridgeport in describing the transfer of the Virginia Avenue building from the Association to the state. This is simply in terms of the opportunity to avoid the necessity of new construction through state purchase of an existing facility (p. 21).⁸ Thus, the existence of any issues in the interaction between public and private agencies, or any question about why the transfer occurred in the light of a call for "partnership," are not mentioned.

"The Regional philosophy" is described (p. 242) as "an approach which has been placing increasing emphasis on the maximum provision of services to the retarded by generic community agencies." It is striking that no reference is made to the significant Project in Bridgeport which was intended to embody this formulation throughout its operations.

⁷ (See also p. 222 of Miles to Go where the "Residential Proposal" of the Bridgeport Regional Center is Presented.)

⁸ Other references to the transfer occur on pages 16, 19, 207, and 208.

The Report's section on "The Role of the Professional" (pp. 241ff) discusses mainly the jargon of "jargon-cultists: and calls for an "intra-mental" retardation association to provide experiences for professionals that would permit exposure to other disciplines and the surmounting of "single-discipline" associations. "The various disciplines," it reports (p. 248) "are already making significant contributions..." but "the basic content of the new synthesis in social welfare, health and education will not ...emanate from a single discipline or even a single field, such as mental retardation." Specialists, it concludes, should contribute to a dialogue and function primarily as generalists in a constant and continuous, rather than episodic, fashion.

The succeeding chapter on "The Role of the Volunteer" begins with a reference to the tradition of service in American culture, and turns to a discussion of what is seen as the "manpower shortage," and the crucial of the "volunteer and the paid semi-professional or non-professional." "Ingenuity" in the use of volunteers at training schools and regional centers is illustrated. The Parents and Friends are used as an illustration of how "local associations for retarded children [have] made extensive use of volunteers." Adult volunteers for pre-school classes; adult volunteers for the Nearly New Shop, "a consignment shop"; teen age volunteers for a recreation program; volunteers for clerical and receptionist duties and for fund raising; visitors to homes of newly-identified retarded children, to supplement the work of the clinic and social workers, are all listed. The "responsiveness of young people in particular to the needs of the retarded" is described, through the response of 300 high school girls to a bulletin board notice in three local high schools for help in pre-school and day-care programs in the summer. Finally, "labor union members contributed hundreds of hours' labor in construction of the first Kennedy Center." (p. 253).

"The mere presence," continues the report (p. 255), "of volunteer workers -- untrained, unoriented, having only affection, energy and common sense to contribute -- is in itself a boon and a blessing to any facility or service for the retarded, public and private." (p. 255). After reference to "companionship, warmth and a natural talent for imparting the lessons of life." (p. 255), the necessity of providing training for volunteers is discussed. Shortages of professionals and skilled personnel and the increasing sophistication and complexity of programs are the reasons given.

It is significant that the report observes that

...no association for the retarded has ever conducted a thorough, professionally directed, carefully conceived training program for such a program at the community level. (p. 257).

This aspect of the Bridgeport Project's activities or intentions was not included. While such a program had been one of the efforts proposed for the Project of the Parents and Friends association, the lack of reference in this state planning report indicates that it did not materialize.

A significant hortatory conclusion in the chapter on "The Future Role of ARC's" called for cooperation among multiple sources of inventiveness in the provision of services

and opportunities for the retarded.⁹ The section begins with an allusion to the alleged rigidity of government.

Official agencies and institutions often lack the latitude and the flexibility to generate and maintain programs which, to both the enthusiastic proponent and the detached observer, seem from every perspective to warrant immediate establishment. (p. 265).

The resolute heroes who move the immovable are portrayed as the associations of volunteers who are presumed to be the generating locus for new ideas and the center of the implementing and energizing force.

Local associations for the retarded -- sometimes in cooperation with other community agencies and with financial support and guidance from OMR -- are often in an excellent position to initiate and accomplish that which the strictures and rigidities of government make -- at least for the time being -- impossible or impractical.

The associations might sponsor, it is said, "a rich harvest of suggested activities and services which have an urgent, immediate applicability". (p. 266) A "wide range of demonstration, pilot, or interim programs which ARC's might sponsor" is said to exist, but no specific reference to the Bridgeport Project is given.

No reference is made at this point to possible rigidity by parents associations, nor to the conceivable appropriateness of parents' associations acting to implement programs initiated in the first instance by official agencies and institutions. No legitimacy is expressed for participation by the individual member of a local association in activities and services other than those which have "an urgent, immediate applicability to him and his association." The paragraph containing this concludes by an allusion to the possible instrumental function of associations in bringing about major advances for the retarded, but avoids any implication that ideas for major advances might come from establishments such as government.

The appraisal of the functions of the local, voluntary association continues with the statement that the state Office of Mental Retardation¹⁰ "...neither aspires to become,

⁹ Pp. 260ff, especially 265-267, in Miles to Go.

¹⁰ This is defined in the text as the central office in Hartford, the training schools, regional centers, "and other facilities that come under the panoply of OMR and its 'parent' department, the State Department of Health," thus covering the total range of government dealing directly with retardation.

nor should become, a monolithic force in the mental-retardation field in Connecticut." Apparently, the authors of the Miles to Go report felt some danger of this existed.

Progress in the provision and generation of services for the retarded would come, they continued, from "many sources" of "creative programming", "constructive criticism", and "cooperative activity" existed. "Looming largest among all these sources which must supplement the functions of OMR are the state and local associations for the retarded." (p. 266) There is no suggestion that associations might possibly not function to generate new ideas, or that their efforts might involve programming that could be non-creative or self-serving, criticism that might not be constructive, or activity along independent rather than cooperative lines.

According to Miles to Go, certain virtues are "demanded" of "layman and professional, public agency and private association alike" so that the "multi-pronged effort" may be maintained. These virtues are "self-discipline, sacrifice, imagination, mutual respect, and a capacity for compromise."

Of the layman .. [maintenance of the multi-pronged effort] demands that he yield to the processes of constructive change--that he not try to maintain a tight grip on functions and prerogatives which must rightly pass to the professional as the mental-retardation field becomes increasingly professionalized and must rightly pass to the regional center and regional program as the "public sector" of our field expands.

Of the professional it demands that he prove his professionalism not by aggressively or ostentatiously asserting it, but by demonstrating it in the subtle ways which are the hallmark of the master craftsman in any field.

It demands that the parent forego resistance to innovation merely for the sake of resistance; that the professional abstain from attempting to manipulate or use parents in a cynical or contrived way. It demands that professional and layman alike be willing and able to accept criticism and consider new ideas as constructively and as gracefully as they are offered. (p. 266)

Not mentioned in the text, however, are concrete rules and criteria for the determination of (a) what is constructive change, (b) what should pass to regional centers, (c) how to avoid the aggressive or ostentatious assertion of professionalism, (d) the subtle demonstration of any undesirable professionalism, (e) the manner of avoidance of pointless resistance to change, (f) the manner of avoidance of manipulation or the "using" of parents by professionals, and (g) means for internalization of the willingness and ability to offer and to accept criticism and consider new ideas constructively and gracefully.

On the Eve and At the Outset of the Project

Major issues that confront voluntary associations concern their involvement with

government and with the community. We have referred earlier to the expression in Miles to Go of the "regional philosophy" as involving "increasing emphasis on the maximum provision of services to the retarded by generic community agencies." ¹¹

New Programs may bring individuals from the public at large into the affairs and projects of an association who were defined by members as outsiders. The intrusion of outsiders, served by and interested in the various projects and services, could threaten the patterns of friendliness and neighborliness that had developed around the Association, in its many committees, planned events and social affairs, and could impinge on the Association's achieved place of authority within the community.

Efforts were in fact made to involve people from the community in the affairs of the Association by membership on the Board. Yet, as two parent members pointed out,

...it never worked out. They never came, and could not be on Board committees. Maybe we did not pick the right people or they did not have the time. There were one or two a year.

Such experiences with non-members by dedicated members would not be surprising and can be seen in many voluntary associations. Few however are manifestly committed to the development of ties with the community as was this Association by virtue of its Project. Some ambivalence about "outsiders" did undoubtedly exist.

Extensive activities were characteristic of the Association during the years preceding and during the first year or two of the Project. Intense local efforts had been crowned with success at an early point. It has been said by various informants from this period, "We got the first trainable class for the mentally retarded in Connecticut." "We were the first in so many ways." "We did things and showed the way." The list of achievements included, in addition to the trainable class, a parent-sponsored diagnostic clinic for the retarded, recreational programs, and an extensive day care program.

Of vast significance in cementing social ties among early Association members was its construction through volunteer participation, of the first service building in Bridgeport in 1954. This was later followed by major efforts at fund-raising, amounting to approximately \$400,000 that ultimately made it possible to design and have built Kennedy Center, on Virginia Avenue which opened in 1965.

How the Project staff of the Association formulated their concern for community involvement is of central importance. Here the -- criticism -- of a key community actor af-

¹¹ Pp. 260ff, especially 265-267, in Miles to Go.

filiated with the Association and the Project highlights the issues involved in moving toward a transfer of services from initiators to others.

[The Project]...found very little volunteering. [It] got slews of volunteers. [We]...wanted to get the organizations in the community involved, such as Kiwanis, some women's organizations, Catholic organizations. We were getting started.

Some question on this point lingers, for parents now claim that many people from the community were active even before the Project began. Scouts, religious groups and others helped in various day care programs. Yet this participation appeared sporadic and irregular to the Project personnel who apparently believed a large potential remained untapped.

In the eyes of Project personnel, the simple but far-reaching goal of involving the community countered behavior patterns and attitudes, even within the Association itself, that were difficult to overcome.

...[The] job was to involve the community. ...The parents did not want the community to participate, they wanted a little organization, a small organization. They said too many people were coming in and were interfering. ...They did not want what they called interference with their plans which were to keep the organization small.

The Parents and Friends were not allowing the Project to function. They thought they had federal funds, they were the boss, and that's it. It comes down to not wanting anyone to take over. They said we should be the small little organization that we were, and we should not let this go on. They were still the same, they wanted to stay little, they were satisfied with little things, a rummage sale, or the store they had. (12/6/68)

Parents assert in contrast that growth was indeed their object.

We never wanted the organization to stay small, we were trying to reach out to involve others.

Yet, the speakers added:

As the new ones came in, they were not part of the original group and did not have the same dedication. They were not told they could not be on committees. That was their choice.

This does in fact raise the question, discussed elsewhere in this monograph, of the often close link of Project and Association in the thinking of those who participated in these intertwined events. Broadening the membership of the Association itself may not have been a purpose of the Project, yet the orientation of the Project toward broadening community services to enhance the public interest was clearly affected in its implementation by the membership feature of the sponsoring Association.

The manner in which the Association's members visualized their involvement with the community in terms of their own personal roles infringed thereby on the Project's operations. Another informant, critical of the Association, stated that participation in the Association had social functions for the members that were unavailable elsewhere.

This became their whole life, and since some of them were not accepted elsewhere by their family and friends because they had a retarded child, they found a new life in the activities of the Association. They spent a lot of time at it, night, four and five nights a week, weekends, all of that. I simply wouldn't do it. (12/7/68)
An abnormal amount of time was thought by this informant to be a requirement for full-fledged participation and acceptance as a "team member."

If this statement can be believed, it would appear that a major function of the Association was the "social returns" for many of those who were active participants in it. Given this, a question might be raised about the likelihood that participants playing such roles would be oriented to the generation of a variety of new programs in the community. Yet, the Project's efforts in the community were supported actively by many parents.

In its overall involvement with the state and other established bodies, the basic philosophy and ideology at the time has been characterized as (a) pro-parent; (b) anti-institution, anti-establishment, and anti-state; (c) pro-change the institution, establishment and state; (d) expansionist and promotional; and (e) anti-professional (as representatives or employees of the establishment). A fundamental belief was that society had let the retarded down, had not provided sufficient help, was mistreating the retarded and their families, and that this local Association had broken through the discriminatory barriers in Bridgeport.

The prominence of the Association in Connecticut involved a number of unusual and indeed pioneering steps. Mr. Sandahl recently recalled:

People look back to that as a crusading time. From the first there were tangible things getting accomplished. There was a lot of emotion and a great deal of momentum, but it could not continue.

In Bridgeport, the Parents and Friends had the highest rate of participation in the Association of all the cities in Connecticut. There was a zest and a drive, a chemistry that is hard to define. It was the right group of parents getting together at the certain moment in history, but it may have been

self-defeating as you could not expect parents to sustain that kind of effort.

Having the state take over, that was the objective. It was feverish and we had zeal through 1962 and the new people were infected with that spirit.

The specific pioneering steps were reviewed recently in detail with Mrs. Evelyn Kennedy, a key parent leader and an active spokesman whose name was later honored by identification of the Association's service building as the Kennedy Center. Mrs. Kennedy described first the introduction in September 1951 of special classes at the Columbus School, a unit in the Bridgeport public school system. She appeared in the Spring of that year at a Budget meeting of the city's Common Council, identified herself in that public forum as the parent of a retarded child, and spoke with conviction and with success of the need for special education efforts in the city schools for those youngsters who were retarded. Funds for special transportation for those needing it were made available at the time by the Bridgeport Brass Company, a local industry. Mr. Warren Faust, a key company official, was described by Mrs. Kennedy as the first person in the community who provided the help that opened the doors to expanded services for the retarded.

In 1954, the coalescing Association started construction of its own service facility in Bridgeport, located on Williams Street. "Eighty percent of it was built by parents and volunteers," reported a key participant. Donations came from several organizations, including again the Brass Company. Designed by parents, it was dedicated in 1956. Various day services were operated there, but "a high waiting list existed and it kept increasing. We were faced with the decision to move to larger quarters or to renovate. That was considered impractical."

In 1958, the association started to raise money for a new physical facility. About a year or so before, the workshop began and other existing services expanded. "Everyone was willing to help," recalled Mrs. Kennedy, stating, "We had a reputation second to none as the agency that worked for themselves and got things done. ... There was a big community backing and we demonstrated the need at Williams Street."

Looking back on the early period and the later transition toward the Project and the present, one well-known leader in the retardation field recently observed:

They were pioneers, aggressive, with a great flow of ideas, and this is not conducive to the orderly flow of business. Tools for breaking ground are not the tools for the lawn. They are rough tools and they're not as fine as they should be later on. That was the reason they did not have the staff that was conservative, that would have been the useful staff, but they hired idea men who were too imaginative.

Overall, they played the pioneer role, and that had inevitable consequences. (5/19/68)

Another individual, recalling the early years of the Association activities, noted that the "parent group ...was unique in that it was the first one to regionalize to cover seven towns. They had a very bright guy, a genius, Eric Sandahl, as a founding father who was behind the scenes since 1951."

In summary, on the eve of the Project, the Association had initiated and created a number of striking and pioneering programs of services for the retarded in Bridgeport, provided largely by its own accumulating resources and by others as well with their encouragement. It had constructed one service center building and was engaged in planning another. Its members included key figures in the state mental retardation system. It had ties with the leading national Parents' Association, of which it was a local chapter. It was in contact with the national parents' movement to upgrade the status of the retarded. Its aims were extensive and its achievements in Bridgeport were as solid. Its local efforts were known in the state and nationally.

The Parents Association had accomplished a great deal in the first decade of its existence and moved confidently ahead to new goals. A small group of involved and dedicated parents had indeed changed the system and opened up new opportunities for service and care for the retarded.

CHAPTER VI

THE DEVELOPMENT AND OUTCOMES OF SELECTED SUB-PROJECTS: A DESCRIPTIVE ANALYSIS

Any analysis of the undertakings and the achievements of the Project rests, in the last analysis, on the judgments of key participants in those groups in Bridgeport that deal with or provide services for the retarded.

Changes in the structure and operation of services will surely have taken place in the period of five years from 1963 to 1968. Description of current organizations and their services, as provided by informed participants and observers, will yield information both on the present and the past. The analysis of change requires some interpretation of what things were like in the past and what they are like at present.

Accordingly, the Project Writing Staff culled from the initial proposal, from subsequent progress reports submitted in conjunction with the grant, and from other documents, a list of sub-projects or precise changes and developments that were on the agenda of the Project for accomplishment in the five year span.

This list was used as a interview guide with a limited number of persons now in important and responsible positions in the community. Each informant was asked to react to the specific items by stating the following on the basis of his or her detailed experience and observations:

- 1) What is the current state of reality of this particular event or proposal? Does it or does it not exist now?
- 2) How much was done and, if anything, what actions were undertaken so as to implement the initial formulation?
- 3) If it was not accomplished, what were the reasons? What were the barriers that existed, if any, that were seen at the time as blocking or likely to block the proposal?
- 4) What specific part did the Project itself and its staff play in actions related to whatever achievement was reached for each proposal?

Key informants either (1) are or have been major actors in the changing retardation scene in Bridgeport through the last 10 years; (2) are or have been important participants in the affairs of the association and of the Project; and/or (3) hold responsible positions in the major service providing agency in Bridgeport.

They included the current Executive Director of the Parents and Friends Association; the current Director of the Regional Center; the current social worker, head of community services at the Regional Center, who also was a former member of the Project's staff from the time of its inception; an active member of the Parents' Association and its Board from the time of its founding who was prominent in the formulation of Kennedy Center programming; and another long-time active member of the Association and its Board.

These informants have experience and background in retardation services, perspective on the community and familiarity from participation and observation, with the Association and other agencies in the community. They all play responsible parts as employees or volunteers in retardation services.

Criticism may be directed to the reliance on persons who were new to Bridgeport or to their position or responsibility. The Executive Director moved into that position in January 1968. The Regional Center Director came to his position in Summer 1965 when the state acquired ownership of the Association's Kennedy Center building. Their official experience is therefore recent and hence their involvement in and knowledge of events preceding their current job are of necessity indirect or second-hand.

Their administrative roles would, however, entail awareness of the events and phenomena listed below, if they were continuing or had been created. The two individuals listed have the greatest local responsibility as professional employees for mental retardation in the Bridgeport area and are in a very critical position to report what exists, to assess its worth and to identify areas where needs are still unfulfilled.

During most discussions with the Regional Center Director, and during the particular meeting when the data reported later in this Chapter were collected, he was joined by the Chief Social Worker of the Center. This individual had been employed by the Parents and Friends in many capacities as long ago as 1960. His affiliation with the Association continued through the transfer of ownership of the building when he joined the state-employed staff located there. Thus, his familiarity with retardation services reflected a prolonged and varied set of roles and complemented the gaps in experience of the Center Director. They were interviewed jointly. The Association's Executive Director had personal affiliations with the Association's efforts for some years prior to coming to its highest position.

The Project, of course, was planned in large part to create new efforts and services. An illustration is the Information Kit, one of the items on the list. When the Executive Director, Regional Director and his staff, or a parent leader states, "I never heard of it," an explanation may be that the event took place several years before, or, of course, memory was faulty. As in many such instances, however, the Kit if developed was supposed to be maintained. If recently responsible personnel are unaware of it, then it was not maintained and the sub-project to develop a Kit might be adjudged a failure.

Overall, then, the individuals chosen to represent reactions to the sub-projects presented here are the obvious and essential persons for the task.

The Chart presents summaries for the life of the Project of the sub-projects derived from the Proposal and subsequent related documents. Also included are appraisals of the

current or past state of development of each sub-project. Certain sub-projects of the overall proposal were selected for analysis by these informants and serve as illustrative indicators of achievements. The appraisals are taken from the statements of the informants who were individually asked to answer the questions given above about each one of the sub-projects.

We present (1) the sub-project as the heading for each section; (2) a summary of it from the Proposal and later Progress Reports; and (3) the reactions of the key persons interviewed. These reactions are usually given individually and in sequence.

The Appendix to this Chapter provides first, a summary of each sub-project drawn from the Project Proposal and then specific statements about the sub-project from each of the annual Progress Reports, and, second, the comments and appraisals made by each of the key community actors who were interviewed. These materials are rather voluminous, and accordingly it was thought best to present them in detail in the Chapter's Appendix for those who wish to examine them first-hand.

The Chart in the body of the Chapter presents a summary of the comments that those interviewed provided when asked about each specific sub-project. It identifies first the sub-project by title, and then lists in the second column the sources in the Proposal itself or the subsequent Progress Reports of the Project, classified by year, from which we were able to prepare the history of each sub-project.

The other columns of the Chart contain summaries of the appraisals provided by each respondent. The history of each sub-project and the comments are more fully presented in this Chapter's Appendix to provide the reader with an opportunity for their direct examination.

The items in the chart reflect, in illustration but in detail nevertheless, the life of the Project as it continued throughout its span.

At this level of sub-projects, the Project overall does not seem to be overly successful in effecting its goals. A number of the items were initiated and then dropped. Some did not continue in any substantial fashion and finally were dropped. Others were apparently never initiated.

Yet, something must be said in defense, so to speak. Two points may be made:

One, organizations are given degrees of latitude by granting agencies that permit alterations of effort within the overall format of supported projects. In demonstration grants, perhaps more so than in research, although it is found there as well, the project proposal is seen, both by the giver and the receiver, as a statement of intent. Contingencies, unanticipated events, accidents, changes in staffing, administrative and other changes of many kinds, affect the course of efforts such as projects.

Accordingly, it is not possible to state with any great conviction that the non-achievements recorded in the Chart represent failure of an outright or blatant sort. There certainly were many such non-achievements, as well as achievements. The illustrative list given here

CHART 1: SUMMARY OF SUB-PROJECTS AND OF APPRAISALS BY KEY COMMUNITY ACTORS

	Sources in Proposal and Progress Reports	Executive Director of Association	Regional Center Director and Staff	Parent Leader	Parent Leader
1. Directory of Services	Proposal 1964	No information, none exists	None	Never saw it; none now	No knowledge
2. Information and Referral	1965 1966 1967	Discussed, never established	Started but never com- pleted as staff member responsible left	None exists	Started but never complet- ed as staff mem- ber responsible left
3. CARC Report	Proposal 1965 1966 1967	Existed, but un- certain about specific early role	Existed, un- clear about activities	No direct aid to Parents & Friends	Uncertain lo- cal benefits, some benefits to state
4. Written Materials Program	Proposal 1964	No information	No inform- ation	Discussed, nothing developed	Discussed, nothing developed
5. Public Health Nursing for Retarded	Proposal 1965 1967	No current activity	In service early in project, but discon- tinued	No current link between PHN and P & F	Early seminars, survey, no in- volvement since 1966
6. Visiting Services to Other Communities	Proposal 1964	Nothing now, some limited at beginning	Never heard of this	Idea, never implemented	Never carried out

CHART I (continued)

	Sources in Proposal and Progress Reports	Executive Director of Association	Regional Center Director and Staff	Parent Leader	Parent Leader
7. Community and Professional Lecture Series	Proposal 1964 1966 1967	Nothing now	Planned, but never happened	Few at start; none now	Not aware of such a program
8. Parent Education and Counseling Program	Proposal 1964 1965 1966 1967	May have occurred; nothing now	Planned, but limited program terminated	Limited pro- gram termi-	Limited program terminated
9. Training of Volunteers (Leadership Training Workshops)	Proposal 1964 1965 1966 1967	No informa- tion, nothing now	No know- ledge of any effort	Idea not developed	One program never repeated
10. Research Activities	Proposal 1964 1965 1966 1967	None now; some in past	Limited re- search, but basic idea never implemented	Limited re- search, but basic idea never implemented	Never imple- mented

should be examined in conjunction with the overall list of sub-projects and their accomplishment provided in the chapter on Conclusions below.

A record of non-accomplishment is suggested, at least for many items on the list given here. Yet, the Project staff and the Association sponsors may have adapted to the local reality of Bridgeport and pursued change in other directions. Such re-directions are sanctioned, it appears, by granting agencies.

Two, the Project as a whole should be viewed and appraised both in terms of specific lists of sub-projects and in terms of its overall significance. On the former, the record is frequently one of non-fulfillment. For the latter, it must be stated that with all of its problems the Project as a whole nonetheless symbolized for many in Bridgeport a continuation of the social movements in that community toward the improvement of the situation of the retarded. It symbolized change and represented forward movement.

APPENDIX

Sub-Projects

1. Publication of a Directory of Services Available in Bridgeport for the Retarded.

Summary from Proposal and Progress Reports

The proposal included the publication of a Directory of Services to the retarded in Bridgeport for distribution to social agencies, physicians, clergymen and others as part of its "first year program".

This was mentioned also in April 1964. In the July 1965 and July 1966 Progress Reports, no mention was made of this Directory.

Comments by Key Community Actors

- a. The Association's Executive Director stated that she had no information about such a Directory, that there is none in the community, though the Office of Mental Retardation in Hartford may have one available for the state.
- b. The Regional Center Director and Staff stated that there is none in Bridgeport that concentrates on the retarded. The United Fund, he added, has had a Directory of Community Services since 1966 and he feels this is adequate. Some time in 1964, a Project staff member (Donaldson Tall) was hired to set up an Information and Referral Service. A Written Materials Program was developed to collect and distribute pamphlets on retardation to parents and many were purchased for such purpose. The Association, they state, is supposedly still providing such materials. A special amount of money was allotted under the Project for this purpose.
- c. A key parent-leader reported not having seen such a Directory and affirmed that there is none now.
- d. Another key parent-leader reported having no knowledge of such a Directory "... except for what [a staff man]... did.", adding a reference to the Written Materials Program but concluding this by stating, "I don't know what the results were."

2. Information and Referral Service.

Summary from Proposal and Progress Reports

In July 1965, the Progress Report stated that "to have an effective community-based

program, a "fixed point of information and referral" should be set up. It would involve, continued the document, gaining the confidence of local agencies in order to gather information on retardation cases in the area.

The document added that a "comprehensive community-based program would be unfeasible" unless an information and referral service were established. In 1965, a single social worker acted as the "fixed point" in the Bridgeport area. The I & R Service as projected then would offer advice and assess the potentiality of particular agencies to aid the retarded. It was stated that everything necessary to establish such a service had yet to be done.

The July 1965 Report observed that the service was recommended and accepted as a responsibility that the State should assume (presumably when the state established its Regional Center through purchase of the Virginia Avenue Kennedy Center building.) No statement was made about the state's efforts to that date.

In July 1966, the Progress Report stated "...the functions of the service have not been well established." The Report continued that the Kennedy Center clinic then in operation should not have responsibility for this service, that it should run such a program until the state or community would take it over.

In July 1967, the Report stated that the Information and Referral Program had been "re-evaluated" and appeared to be a contradiction in purpose." "Although the initial concept had been to channel referrals of retardates to appropriate agencies for services, information provided the community through brochures indicated agencies should refer the retarded to Parents and Friends." A new "Information and Referral Follow-up Program" was proposed and discussions for such a development were said to be under way under the ad hoc chairmanship of the Project Director.

Comments by Key Community Actors

- a. The Association's Executive Director stated that "nothing was set up. An ad hoc Committee existed in Summer 1967 for discussion by representatives of different agencies for the purpose of deciding how to set up an Information and Referral Service. ...As of 1967, how to do this was still being discussed. No conclusion was reached. There's no fixed point of referral in Bridgeport in September 1968."
- b. The Regional Center Director and Staff stated this idea was an outgrowth of the Directory of Services. A Project staff member wrote a Directory of state agencies and they sent out brochures. "It did start up at the Kennedy Center, but Tall quit and that finished it." "It is still being discussed."

Here the Director and his staff member expressed disagreement about whether the discussions in recent months were confined to or simply included the retarded in the network of services. The "original concept" was that Information and Referral Services would be for professionals and agencies in the community rather than for parents. The Regional Center informants agreed the program "died" when the Project staff member assigned to the

task left the organization.

- c. A key parent-leader stated that there is no Information and Referral service as such, and that no fixed point of referral exists. "The Volunteers Bureau has a directory of agencies and described services in Bridgeport." "The Kennedy Center was without hesitation a fixed point of referral and the trend is toward the Regional Center. The Clinic is here and the public schools refer children here." ¹
- d. Another key parent-leader stated that one of the Project staff "...worked on that. There is no Information and Referral Service in Bridgeport now and there is no fixed point of referral. The Regional Center is becoming more so, but ...they're more involved with the younger children."

3. Contributions by the State Association to the Project.

Summary from Proposal and Progress Reports

The Proposal included support in its first year for a new staff position of Community and Program Consultant at the Connecticut Association for Retarded Children, (CARC) "to serve as consultant to local associations and communities, especially Bridgeport, in strengthening, enhancing and coordinating state wide programs and services." In addition, a "part-time public relations consultant" was to be hired by C. A. R. C. with Project funds in the second year of the Project.

The July 1965 Progress Report stated that the CARC support from the Project "confirmed" the proposal's prediction that a "strong program within the Connecticut Association for Retarded Children" would help establish the eventual success of the Project in setting up a comprehensive community-based service, would provide necessary legislative support for the "...programs to be phased out during the life of the project." This Report also referred to an output from the Project through the Association to the state, as follows: "the staff of the Connecticut Association for Retarded Children gave especial effort to introducing the program method and techniques generated within the project to all areas of the state."

The July 1966 Report stated that the Program Consultant began work in March 1964 "with primary responsibilities for functioning in the fields of vocational rehabilitation, education and sheltered workshops...", and that "...initial activities in these areas have led to involvement in the inter-related aspects of the mental retardation movement in Connecticut." Other statements in the Report include "The concentrated effort of the CARC has made possible the creation of Bridgeport as a Regional Center. This will create addition-

¹ Such referrals from the public schools were stated by the Regional Center's Director to be very limited. The public schools provide little if any data to the Regional Center on Center clients who also may be enrolled in the schools.

al components for the comprehensive model and free Project monies for new services. Last year the CARC created an organized program of public education on a statewide basis. This is important in that it defines the new and major role of local Associations. In addition, it provides the broad basis of community support for our total Project program."

The July 1967 Report referred to the strengthening of the CARC's role in "translating the philosophy and goal of the Project to other areas of the State" and attributed this to the filling of the Program Consultant's position in April 1967 and the continuation of the CARC Executive Director as a member of the Program and Project Committee of the Parents and Friends Association. Project funds allotted to CARC were stated to have supported two studies: (1) a follow-up of 135 DVR rehabilitated mentally retarded clients and (2) a five year follow-up study of young adults who had completed a Special Education program in Norwalk schools.

Comments by Key Community Actors

- a. The Association's Executive Director stated that this was an on-going part of the Project but expressed lack of knowledge about the precise manner in which the CARC had, as stated in the July 1965 and July 1966 Reports, "made possible the creation of Bridgeport as a Regional Center."
- b. The Regional Center Director and Staff noted that two individuals had been employed in the position. One was, at the time of the interview on the staff of the State Office of Mental Retardation; the other, also at the time of the interview, was in the employ of the state association.
- c. A key parent-leader observed this had "no pay-off" for the Parents and Friends Association. "Little happened" as a result.
- d. Another key parent-leader observed that "local benefits" from this were uncertain although "some contribution" to the state Association's efforts was possible.

4. Development of Written Materials

Summary from Proposal and Progress Reports

The Proposal for the Project identified the "development of an informational 'kit' series for professional disciplines," as a service projected for the first year.

Such a kit for nurses, described as the first in the series, was listed in the April 1964 Report as being developed by Miss Vennert and by Mrs. Muldoon of the Bridgeport Department of Humane Affairs who was assigned as a liaison to the Project. No reference was included in the July 1964 Report, July 1965 Report, July 1966 Report, and the July 1967 Report.

Comments by Key Community Actors:

- a. The Association's Executive Director indicated her lack of information about any such effort.
- b. The Regional Center Director and Staff were not aware of such an effort.
- c. A key parent-leader stated this had been discussed, that the intention had been to send materials to physicians, nurses, churches, etc. but nothing was accomplished. Nothing is being done now.
- d. Another key parent-leader said there were to be brochures sent to physicians, but nothing had been developed as far as the informant knew. The informant related this to the proposal for seminars for physicians and others on the nature of mental retardation.

5. Public Health Nursing for the Retarded

Summary from Proposal and Progress Reports

The Proposal included Public Health Nursing for the mentally retarded as one of the programs to be developed during its first year. It stated that this was "...to be established between Kennedy Center and the Bridgeport Department of Health for firmly establishing home care and training as part of the comprehensive model." In the second year, this was "...to be dropped from Kennedy Center and continued as Health Department function."

By March 1964, consultation with the Bridgeport Visiting Nurse Association for a home-care project had been undertaken, and a Public Health Nursing seminar was planned for the Fall. A survey was undertaken with P. H. N. "...to establish the number of retardates in the case loads. These cases were evaluated with respect to level of retardation and type of placement such as home, school, home and school, or institution." The city Department of Humane Affairs assigned a nursing supervisor as liaison to the Project which obviated the earlier plan to hire a part-time Public Health Nurse. The Project funded Director of Residential and Day Care Services, who was a nurse, "...visited with the Public Health Nursing groups in the Bridgeport area as well as the nursing staff of the University of Bridgeport." Training was said to be in progress by April 1964.

The July 1965 Report referred to an "excellent working relationship" with the city Department of Humane Affairs which "opened the doors of its children's cottage at the... Chronic Disease Hospital to allow for the development of Short-Term care and Respite care" but made no reference to the liaison and training activities earlier listed. Similarly, no reference to the area of public health nursing was contained in the Report of July 1966.

The July 1967 Report referred to "Seminars for Public Health Nurses in mental retar-

dation" as a program initiated in the preceding three years, but contained no indication of continuing liaison, other training than seminars, or whether supervision or consultation was continuing through the liaison staff.

Comments by Key Community Actors

- a. The Association's Executive Director stated that a Public Health Nurse in Dr. Dinan's office was involved in the Project. "About two years ago, [one of our Board members]...wondered what the Public Health Nurse was doing." The nurse liaison was "...on and then dropped off from the Project Committee about 1967 and was not replaced. There is no current involvement." She added she did not know what the program was like when it operated, that there was a probable lack of follow-through after the first Project Director left, "...then there was a dead period, and then ...[the second Project Director] came, and then ...[the nurse] could no longer stay on the committee. She was taking courses." The Executive Director did not know if the Regional Center was working with the Public Health Nurses.
 - b. The Regional Center Director and Staff recalled the "nurse at City Hall [who] developed in-service training." They reported some in-service training programs but did not know if any exist at present. They added that "she was dropped from the Project Committee by 1965."
 - c. A key parent-leader observed the Public Health Nurse was on the Project Committee as a liaison, that there was no liaison nurse currently, and said she had no information about any current aspect of Public Health Nurses' activities that involved retardation or reflected what may have occurred earlier. She added that the Regional Center has a close relationship with the city Department of Health.
 - d. Another key parent-leader recalled that the Project planned to pay the salary of a nurse at first, that Dr. Dinan then assigned a nurse on his staff. "We had seminars and did a survey." "There's no involvement by nurses now and it bothers me. [The Project] ...sent [a staff member] ...to find out what programs existed and how far they had developed by Spring 1966. She went to the nurses and found things were going beautifully." The nurse "...was on the Project Committee but she's not now coming."
6. Program of Visits to Services in Other Communities.

Summary from Proposal and Progress Reports

The Proposal stated that visits to existing programs in other communities would help in education of their committees, that "the program and procedures established in the Bridgeport area will have significant meaning for every Connecticut community." And concluded its account of commitments for the fifth year of the Project with the assertion that "the final year will ...concentrate on the developments of techniques for application to other communities." A program of visits to services in other communities was planned.

The April 1964 Report stated that such visits "...should be encouraged and planned for

our Committee," presumably the Project Committee.

The July 1964 Report makes no specific reference to "these proposed visits" but did observe that "...the project has produced large amounts of written materials. Copies have been sent on to V.R.A. in Washington. ...We believe that a great deal of this material and the additional documents now being prepared, have great significance for many communities across the nation."

Comments by Key Community Actors

- a. The Association's Executive Director stated that the previous Project Director did some visiting and the first Director may have, but was uncertain whether this occurred, because of the Proposal's inclusion of this item or because of the individuals' experience and reputation. No such program existed in 1968. The Project staff "responded" to calls for information, forms, etc., from nearby local and state associations and professional groups. For example, the current psychologist lectured to nurses and the previous Project Director participated in a workshop in Vermont. The current Director was aware of few such calls from other groups.
- b. The Regional Center Director and Staff were not aware that this program was part of the Proposal or the Project.
- c. A key parent-leader stated, "We were supposed to go; the Residential Committee was supposed to go to all the residences in the area; the Workshop Committee and Board were supposed to visit workshops. This was not done. We were all hopped up at first, we could see this as rewarding and beneficial to others but we didn't get to do it. The granting agency said that they would like to see this; it would be a joint benefit to Parents and Friends and others. It was all wonderful, but it's sad; we were so eager and now we realize what we could do. But with the mess and upheaval it went down the drain. We could have been the Bible on mental retardation."
- d. Another key parent-leader stated the "U.S. wanted some money in the Project to be sent to visit other communities and we never did. We felt guilty about the money and the time."

7. Community and Professional Lecture Series.

Summary from Proposal and Progress Reports

The Proposal included lectures with the aim of demonstrating "...the effective use and relationship of local universities to a model of comprehensive services."

In April 1964, a Progress Report stated that "the first in this series will be on May 15, in conjunction with the University of Connecticut, School of Social Work, on 'RECREATION.'"

The Progress Report covering 1963-1964 reported that "...a special statewide workshop was held by the Project on the use of 'Group Work Skills in Work with the Retarded.' The workshop was co-sponsored with the University of Connecticut, School of Social Work."

The July 1966 Progress Report listed "training institutes in cooperation with colleges and universities in the area" as one of a series of "potential expansion areas for Kennedy Center."

The July 1967 Report referred to universities as follows: "The Project was involved in consultation with Fairfield University which has initiated a graduate Masters Degree program in Special Education, and discussion is going on with the University of Bridgeport regarding an undergraduate program." It made no reference to a community and professional lecture series in conjunction with colleges and universities.

Comments by Key Community Actors:

a. The Association's Executive Director stated, "There is nothing now. ... [The former Project Directors] discussed that idea, they were going to have a program for general practitioners and give them so many hours of training, but we didn't do it. [One of our staff] ... spoke to the nurses several years ago. Oh yes, a team of people from Letchworth Village visited us in 1966 or 1967 for a day or so, to look at our facilities, and [the Project Director] ... lectured to them."

b. The Regional Center Directors Staff observed that "that was planned but with the upheaval and then the crisis that followed it never happened." They referred to several specific University activities or affiliations of staff: (1) the current or recent involvement of Dr. A. Knepler of the University of Bridgeport who developed a program of sex education for parents of the retarded; (2) consultation by Dr. Seymour Sarason of Yale to the Project's first Director; and (3) consultation by a Dr. Fran Kaplan in the area of parent counseling; and (4) the May 15, 1964 Institute for social workers.

c. A key parent-leader said, "No, there's nothing now. [The first Project Director] ... went a few times, and we had an active Speakers Bureau, but we didn't continue it. We were going to give seminars for doctors, teachers, young parents as a group on sex education, and we had a few, but that went by the wayside. Not completely of course, as [the Director] ... served on various panels but we had done that before the grant. He gave it professional stature."

d. Another key parent-leader said she was not aware of such a program.

8. Parent Education and Counseling Program.

Summary from Proposal and Progress Reports

The proposal referred to "community diagnostic treatment clinics with professional counseling for parents; ... home counselors to help parents in training the infant and child in the home," as important services stressed by the National Association for Retarded Children (NARC) for inclusion in comprehensive services. In another section describing implementation strategies, the proposal stated that a "study group" dealing with "special services including diagnosis evaluation, and counseling services" would be established. In a section describing activities projected for the first year of the Project, one of the new programs planned with community agencies was shown to be "Parent Education and Counseling Programs: to be established with Family Service and Child Care agencies." In the second

year this was to be continued "by Family Service and Mental Health Agencies."

The Proposal also listed as a "specific aim" the defining of ...the needs of families of the mentally retarded and to transpose these into services making maximum use of the family structure as part of the training process. It quoted with approval, as goals of the NARC, the provision of "community diagnostic-treatment clinics with professional counseling for the parents" and "home counselors to help parents in training the infant and child in the home."

It stated further that the Kennedy Center already provided such services, as follows: "A full-time family counselor is available to assist families with any problems they may have relative to their retarded child. ...The Counselor is available to any family to help and advise them in getting assistance to work out or avoid any problems."

The April 1964 Report referred to the hiring of a Clinic Director as of June 1, 1964 who would begin to define "...the aims and objectives as well as the role of the clinic in our projected comprehensive service." A Service Specialist (Group Therapist and Education Consultant) already hired was said to have "...now developed group counseling services within our Workshop and has been an invaluable aid to our clinic staff in designating recommended educational programs for the cases discussed at the clinic meetings." A Parent Education and Counseling Program was scheduled "...to be established with Family Service and Child Care agencies....Family Service Agency in Bridgeport...is now in the process of developing group counseling programs for all parents."

The Report for the year ending October 1964 referred to "new parent education and parent counseling programs" as one of a series of "new developments." This was repeated in the July 1965 Progress Report.

The July 1964 Progress Report referred to the addition of a psychologist "...to develop counseling programs for parents as well as therapy opportunities for mentally retarded persons requiring help with emotional problems."

An internal July 1965 Summary of Project Events referred to "explorations with Children's Bureau to develop a Project for Parent Education and Parent Counseling."

The July 1966 Progress Report referred briefly in a description of the Clinic to "...program recommendations for the family and the child." Identified as one of a series of "potential expansion areas for Kennedy Center" was "intensive program development in areas of parent education and clinically therapeutic treatment programs for parents."

The July 1967 Progress Report referred to "clinical counseling" and amplified this by referring to the "initiation of (1) sex education seminars for parents, and (2) a therapeutic counseling program for retardates in the Workshop, under the supervision of the Clinic Director. ...Parents and young adults, sixteen years of age and over were invited to participate in a four-to-six session group counseling programs, which also included one clinic staff member. The parents discussed the need for developing a series of similar programs for the young adults at the Workshop."

Comments by Key Community Actors:

- a. The Association's Executive Director stated that she did not know if any contact was made with Family Service and Child Service agencies, that this may have been done before she assumed the position. A staff social worker, she reported, may have done some parent counseling, and added, "When the Regional Center came, Parents and Friends had some coffee with parents who met at different homes." A consultant social worker, she added, worked on sex education and came in to lecture and guide seminars. A university sociologist was also described as being involved, in the sex education counseling. "But, there's nothing now. I don't know if the Regional Center is doing anything."
- b. The Regional Center Director and Staff stated that counseling was planned but the upheaval and the following crisis disrupted it. A sociologist, they reported, ran a sex education program with parents, and a consultant to a former Project Director helped on parent counseling. Two phases were identified: (1) parent counseling, but "the Parents and Friends don't have professionals now to do anything on it," and (2) there was some parent counseling by other parents but "that died".
- c. A key parent-leader said, "Not much was done. We had a sex education series for parents, but there's nothing now, except at the Regional Center as Social Service counsels parents in the home and at the clinic." "We still get telephone requests from individuals. People want to talk about their problems, but that's not part of the Project. It goes back to early relationships we had, when people wanted to discuss the problem on a personal basis."
- d. Another key parent-leader stated, "There was a series of meetings with parents," by a psychologist and sociologist on sex education. "We got nowhere with Family Services; the Project Director ... tried and could not get anywhere with them."

No detailed reference was made by any of these informants to counseling and therapeutic programs provided at various times by the Kennedy Center Clinic staff for parents of the retarded adults and for the children themselves.

9. Training of Volunteers (Leadership Training Workshops)

Summary from Proposal and Progress Reports

The Proposal included the demonstration of areas for effective use of skilled and trained volunteers in a program of comprehensive services, and, as "specific aim," the demonstration of "...the ways in which communication, cooperation and coordination between professional disciplines and volunteer groups can be increased for maximum use of all community resources in developing services to the families of the retarded."

It added, "Deeply rooted in the Connecticut philosophy for the retarded individual is a shared responsibility between parents and the community. ...Skilled volunteer services can enrich programs and increase supervision of children and adults. ...The selection of volunteers and the proper assignment of volunteers for most effective use with the mentally retarded needs study, development of techniques and documentation." "On a broader level, the involvement of volunteers in a program provides greater exposure of the mentally re-
retarded needs study, development of techniques and documentation." "On a broader level, the involvement of volunteers in a program provides greater exposure of the mentally re-

tarded to the community. The Bridgeport area does have a Volunteer Bureau as part of its Community Council which can be enlisted for help...."

The Proposal listed "volunteer training programs" and "leadership training workshops" as one of the "first year programs", and for the second year programs projected "volunteer training, consultation services and public and community relations programs to be continued and expanded." It added that "the documentation of the process dimension will cover ... recording the interactions between the community and the project, between the project and the agencies involved, and between professionals and lay volunteers staff."

The April 1964 Progress Report recorded the hiring of a Service Specialist who "... will also have primary responsibility in designing and carrying out recruitment and training programs for volunteers," and identified as well Leadership Training Workshops as a program "...now being initiated by CARC".

The July 1964 Progress Report listed "volunteer and professional training seminars and workshops" as one of a series of activities for the first two years of the program, during which time there would be a focus on "staff development to make available the necessary personnel to carry on [such activities]."

The July 1965 Progress Report referred to "the beginning of leadership training and development at the board level" as one of the "additional developments" within the Kennedy Center programs.

The July 1966 Progress Report stated that "as the pressures of the building and program services needs grew and the building program was completed, the need of the Association for dynamic, imaginative leadership became more and more obvious." This Report summarized developments in the Association and the Project and highlighted problems that developed as various perspectives clashed. It noted, "...the Project ...continued to develop demonstration programs in the community and with community agencies. At the same time, the Association committees in program services continued to function and also looked for avenues of development and implementation. This began to cause some feelings within the organization between parent members and the professionals in the Project." The Report continued:

A relatively "new" member was elected president. Since the founding of the Association in 1951, a core group of people, parents of retardates, were the leaders of the Association, and generally the key members of the Board and the Committees. Within the organization there was some feeling among "old" and "new" people and the newly-elected president felt "new" members should become more involved. Among professional workers in the field, ...the implication is that "emotionally involved" people tend to allow these emotions to govern their decisions in developing services. In the philosophy of some professional persons, there should be little direct parent Board or Committee participation in program development, but a power structure of community people should consult in this area.

...Between the Project Director -- who felt the parents should be

spread out and other non-affiliated persons should be brought in as Board and Committee people -- and the President who felt the "old timers" should be moved over and new parents and non-parents brought into positions of responsibility -- a natural alliance was formed.

...The Project recruited as Director of the Clinic, a psychologist out of a mental hospital program. As Clinic Director he felt the Clinic should have total control of the referrant. ...In addition, the parents of the Association, who still felt they had a policy role to play, were also struggling for a role in the program.

...there had been discussion of the establishing of an institute for training sub-professional persons in the field of mental retardation. ...A committee of volunteers was recruited to consider the possibility of creating an independent non-profit association to make application for this institute. When the Association learned of this, they felt this was violating the relationship between the professional staff and the Association. The hostility between the Board members and the professionals was too great to overcome and the Association requested the resignations of the Project Director and the Executive Director. The President resigned in protest....

A new Project Director was appointed who served also as Executive Director of the Association. He wrote in this Report that he felt the joint role provided the "...opportunity to demonstrate the parent, community, state and federal cooperative relationship for programming."

The 1966 Report also noted that "each year the Lane Bryant award goes to an organization for outstanding volunteer service to the community. In November 1965, Parents and Friends of Mentally Retarded Children of Bridgeport, Inc., received this award for the year 1964. The nomination was made by the Governor of the State of Connecticut."

The Report did not refer to "Leadership Training Workshops for volunteers" in any specific fashion and did not include that item in an appended list of "potential expansion areas for Kennedy Center."

The July 1967 Report stated that "the executive director, with the past and current presidents, worked to establish relationships between Board, committee and staff personnel. Meetings were held with volunteers to define committee responsibilities, limits of authority and staff responsibility and authority. Emphasis was placed upon the issue that staff is responsible to the executive director, who in turn is responsible to the Board as a whole and not to any individual Board member."

Another facet of the development of volunteer services that impinged on leadership training was also described in the 1967 Report. In an effort

...to channel volunteer services properly and not duplicate the volunteer activities of the community-based [State of Connecticut] Office of Mental Retardation Regional Center in Bridgeport, and Kennedy Center,

headquarters of Parents and Friends, the need for a well-trained volunteer core, the Board of Parents and Friends agreed to underwrite the salary of a Director of Volunteer Services, on a demonstration basis, and also agreed that this staff person would work out of the Bridgeport Regional Center under the supervision of the Regional Director.

It has been the responsibility of the Volunteer Director to develop, train, and place volunteers to work with the mentally retarded in all agencies providing services, and to follow up the placement with a continuing In-Service Training Program. On May 5, 1967, the Bridgeport Regional Center assumed the position of Director of Volunteer Services as a permanent part of their budget.

Comments by Key Community Actors:

- a. The Association's Executive Director stated that she had no information about leadership training workshops for volunteers, and that the Parents and Friends were not doing anything of this sort now.
- b. The Regional Center Director and Staff reported no knowledge of such specific programs now or in the past.
- c. A key parent-leader stated that the first Project Director and others thought "... it would be wonderful for [parents] to train parents and to counsel parents as an in-between with the referring social workers picking up on the others. But this was not developed. This would have involved other parents also. They were also supposed to do public speaking."
- d. Another key parent-leader reported that the first Project Director "...felt the Board members needed to be educated, and at first he set up a weekend program that was going to be held in New London where we could all get away from day-to-day activities. But it ended up at the Stratfield Hotel [in Bridgeport] as people didn't want to get away. It was supposed to allow a lot of ventilating of feelings. There wasn't any follow up on this at all."

10. Research Activities

Summary from Proposal and Progress Reports

The Proposal devoted nine pages of a total of forty-nine (excluding appendices) to a description of "Basic Methodology" for the Project. This began with the following:

In order to measure the effectiveness of the project a number of major control groups will be necessary. Without a comparison of this kind, it would be impossible to determine the nature of the model or its impact on the community. The major control groups will follow three forms: first, matched control towns for the town of Bridgeport; secondly, matched institution or service; and thirdly, a community or service acting as its own control.

An elaboration of this followed which included procedures for comparing Bridgeport with New Haven and Hartford, and the latter cities with each other. These were to cover such items as comparisons of cases referred to state institutions from each area, of referrals from state institutions to be communities for rehabilitation, and of vocational eligibilities of cases handled by diagnostic clinics and by the Connecticut Bureau of Vocational Rehabilitation in each city. Longitudinal analyses were projected as well, for referrals to and from institutions in each community over a ten-year period, five of which would be within the life of the Project, and for follow-up data on clinic processed cases for ten years in each city.

These controlled studies were to discern the impact of each of the specific aims of the Project, described in the Proposal as the development of comprehensive programs, the implementation of the community base, the further development of the "spectrum of opportunity", the development of more appropriate vocational goals for the retarded, and the "process dimension". The last was defined as follows:

The documentation of the process dimension will cover the natural history of the project in all its relationships. It will involve recording the interactions between the community and the project, between the project and the agencies involved, and between professional and lay volunteers. The course of acceptance of ideas and programs will be one of the main sources of data and only after this has been fully recorded will it be possible to discuss the appropriate analyses.

Further elaboration of these research objectives called for the Project staff to be the "primary source for design and implementation of studies"; its coordination of studies initiated by other agencies; the incorporation of research and evaluation as part of the "normal role" of new staff "at all levels."

Other agencies and universities were identified as prospective cooperative participants for this elaborate research process.

The April 1964 Progress Report described the "Research Program" and listed the following: (1) "the piloting of a physical education program for the trainable retardate" through a public school vocational counselor; (2) completion of "a survey ...to establish the number of retardates in the cases load" of public health nurses that emphasized evaluation and placement; (3) a projected survey of physical, psychological, and social variables involved in adult referrals to the Kennedy Center "...to arrive at recommendations for programming of vocational training; (4) "Community acting as its own Control," by comparing "...earlier analysis of cases tested at the Kennedy Center ...supplemented with a number of social variables ...to evaluate primarily the referrals from towns outside the area and the referral pattern within the seven communities;" and (5) "matched control for particular services," for the matching of Bridgeport, New Haven and Waterbury [information for Hartford was said not yet to be available] by analysis of data from Southbury files on numbers of referrals, placement, and etiology.

The Report dated July 1964 listed the following: (1) involvement of undergraduate students in research, with support from a Summer Assistantship Recruitment Program approved

by the U. S. Division of Chronic Diseases; (2) development of ideas for a summer research assistantship program "...to be submitted later in the form of a complete research program"; (3) "a preliminary survey...of perceptual constancy and its relationship to the functioning of retardates in a work situation" which was said to be "under replication"; (4) submission of a grant proposal to the National Institute of Mental Health for an evaluation of mental health needs of the retarded by coordination of a mental health and a mental retardation agency and by exploration of the role of other social services for mental health needs; (5) a survey of several types of variables associated with adult referrals to the Kennedy Center; (6) completion of a preliminary manuscript to be submitted for publication based on tabulation and analyses of data on admissions and releases from Southbury to Bridgeport, New Haven and Waterbury, showing comparisons for the three cities; (7) completion of a survey of the involvement of agencies with families of the retarded, in conjunction with Public Health Nurses of the Greater Bridgeport area; (8) supplement of "the earlier analysis of the Kennedy Center caseload ...with an analysis of the socio-economic status of the families, which includes income, number of siblings, and marital status," and "it is anticipated that later analysis will focus upon some of the areas of need of the subcultural and deprived groups;" (9) the devising of scales for evaluation of the current level of cases in Kennedy Center programs so that the data "...will serve as a baseline for evaluating the effectiveness of new programs;" and (10) the extension of "...our surveys of agencies and their involvement with the retarded as well as a survey of attitudes of different professional disciplines about working in the field of retardation."

Included in a list of sixteen areas of activity on which "special emphasis will be placed" in the year 1964-1965 was to "continue and expand Research and Training area of activity."

The July 1965 Progress Report stated the following about "Some Research Activities":

The Post School Study of educable retardates was completed and utilized as a mechanism for creating a referral system for the public schools to the Bureau of Vocational Rehabilitation and all other Community Rehabilitation Service. A Professional Study was conducted and is presently being prepared for publication. Sampling techniques and methods for Community Attitude Studies about mental retardation have been prepared. Presently, a follow-up study of 217 trainable adults who have been registered in our educational system is presently in process. This should provide us with information concerning the program needs of this segment of our retarded population.

Other oblique references to data, research and evaluation were included in sections of this Report.

The July 1966 Progress Report covered research in the following fashion:

The [Summer Traineeship Program]...was designed to be a part of the Kennedy Center Project as a continuation of the original program started during the summer of 1964. The purpose of the program was to demonstrate comprehensive community-based services for the retarded

and the initial orientation of the trainees was towards an appreciation of new concepts in terms of service and research.

The aims of the Demonstration Project clearly imply the need for considerable research to provide answers to rather practical questions relative to the establishment of a community-based program for the mentally retarded. Some activity along these lines has taken place during the past year. It seems, however, that much more research of this type remains to be done so that the many spheres of this project activity can be explored thoroughly.

"Research" as such was not otherwise touched upon in the Report and was not listed among twenty-one "potential expansion areas for Kennedy Center." The statement of four of these areas did include the word "investigation." Two did not imply research, however. A research program was no longer called for.

The July 1967 Progress Report stated in a section entitled "Brief Summary of Relevant Accomplishments Presented in Preceding Reports":

...the following research, relating to the needs of the retarded in the community, was initiated: incidence and prevalence of individuals in the area in state institutions; follow-up of graduates of educable classes; professional vocational interest study; preliminary survey of retardates in the case loads of agencies in the greater Bridgeport area; design of a study to determine effect of how parents carried out recommendation of a diagnostic clinic.

And later in the same report:

The State Association also completed two studies conducted with Project funds: (1) A follow-up of 135 D.V.R. rehabilitated mentally retarded clients; (2) a five-year follow-up of mentally retarded young adults who had gone through the Special Education program in the Norwalk, Connecticut public schools. Both studies have been shared with VRA.

In June 1966, Kennedy Center received a request from Yale University, School of Public Health and Epidemiology, to place a Masters candidate in Public Health into the program with the responsibility of developing a Masters thesis under the supervision of the Project Director.

A research project resulted from the placement entitled, "Employers' Attitudes Towards Hiring Mentally Retarded Workers." Fifty-six employers from industrial establishments in the City of Bridgeport were asked to complete a questionnaire which investigated their attitudes towards hiring mentally retarded individuals.

All data were reviewed to identify their implications on future educational programs. Copies have been sent to the appropriate VRA sections.

A follow-up study has been done, to be published, of the 1300 cases seen by the Kennedy Center Diagnostic Clinic since 1956, to determine what their current placements are and what needs they still may have to be met by community resources.

Under "Plans for Next Period" appeared the following reference to research:

With the Project going into its fifth year, a major area will be in the preparation of a series of monographs, describing in detail the concepts, techniques, and implementations of successful programs, as well as descriptive explanations of those programs which have not succeeded.

Other areas which need to be investigated in the coming year include a refinement of data as to incidence and prevalence as illustrated in the survey of needs of clinical cases since 1956. This would be done in association with a study currently being done by the Office of Mental Retardation to computerize all available information on known cases in the State.

And finally:

When the Vocational Rehabilitation Administration Project was initiated to demonstrate broad-based community resources to serve the retarded, the Parents and Friends of Bridgeport were sponsoring all services. The Grant forced the agency to begin turning over programs to community resources without, necessarily, a clear understanding of what impact this would have on the leadership and vitality of the organization. And the vitality of the organization is threatened, it seems to have reduced its ability to maintain its interest and impact on the total program services for the retarded. In the coming year, this will also be studied and included in a monograph.

Comments by Key Community Actors:

- a. The Association's Executive Director reported "there's no research now. ... There's no research being done in Bridgeport by any other agency or group." She provided a list of projects, and stated that the last was completed in August 1967.
- b. The Regional Center Director and Staff stated that "Summer research students did some research in the Summer of 1965 when they were assigned to the Director. But the original research design was dumped."
- c. A key parent-leader observed that "there's little research now. There was some about a year, we had a research director. And there was some at Fairfield University, some IBM research, with Professor Degnan and Father McGrath [a former Clinic Director]."

d. Another key parent-leader stated "We never had a research director who stayed long enough."

CHAPTER VII

EXPECTED SERVICES AND THEIR DELIVERY TO NEEDS

The role of persons requesting services changed dramatically in the history of the Parents and Friends group. The Association began with the recognition that the members and their children needed help. It evolved into cooperative efforts to provide this help through such activities as day care and nursery programs. It developed further to the recruitment of other people, such as professionals, to help operate such programs, and to the raising of money to provide for personnel, services from others, space, equipment and supplies.

In effect, a two-party role set was established, with the collaboration between parents and professionals, and multiple-unit organizational ties were sought, with the effort to engage other agencies and organizations in a broad range of services.

In historical sequence, services at first were fundamentally formulated by the parents. They participated in the delivery of these services by personal actions such as shared child care, activity programming, and the like. They recruited professionals whose help they needed to pursue these efforts, and the professionals also added specific diagnostic and treatment skills through their performance of medical, psychological and other skills.

Organizing the delivery of services meant at this stage (1) learning to define one's own situation (the presence of a retarded individual in the family) in such a way that it could be described and presented to others, rather than being kept as a private affair; (2) learning to relate to and act jointly and cooperatively with others who were in similar situations; (3) channeling those actions and definitions to sanction direct cooperative efforts to alleviate the time demands of the mentally retarded children on the parents and other family members and to provide opportunities for play and recreation, development and learning for the mentally retarded children themselves; (4) recruiting the help of others, some as participants in fund raising and some as participants in services.

The reaching out by parents to others whose interest, intervention, and participation was deemed necessary for the delivery of services took various forms. These included the efforts to get others to contribute funds for general programming or for specific activities. Turning to the United Fund for support of portions of the budget then became an annual process. The solicitation of funds in the community generally through focused events, such as the dances that provide support for the residential centers, was another illustration of the involvement of others. The federal Project was itself a key illustration of how outside support for the attainment of goals formulated within an organization may be obtained.

Outside the area of funding was the use of other agencies to share in the operation of programs, such as day camps, summer recreation, sheltered workshops, and the like.

The participation of volunteers drawn from the community, church groups and synagogues, high school classes, neighbors and friends, was another instance of the involvement of outsiders. Still another was the relationship built into the Project between the activities centered at and generated by the Project in Bridgeport and the intended feedback and mutual stimulation projected for the Consultant associated with the state parents' organization and funded by Project monies.

These reachings out manifestly were expected to increase throughout the life-time of the Project. The Project personnel sought at various times to generate further services for the retarded by numerous public agencies. This was a major thrust and dominant theme projected for the Project at its inception. This meant in effect that the Project focused on intensifying the awareness by the staff of various public agencies that the retarded individuals in the community of Bridgeport were to be served by these agencies. This included the schools, welfare departments, recreational groups, and public health departments.

The approach was simply that an individual who is retarded is nevertheless a person who has the civil and moral right to expect to be served in the same general ways that the non-retarded majority of the population is served. Services of the schools, for example, cannot be withdrawn from a person because he is retarded. Where the retarded individual requires special services, these should be provided. Such services may entail particular emphasis in curricula, such as a program that combines study in academic subjects and training in work skills, and may require as well teachers with the particular backgrounds provided by special education programs in colleges and universities.

Three elements at least define the expectations of services that may be provided the retarded, or indeed any other component of the population defined as in need.

The first is the individual retardate -- his age, his level of retardation, his degree -- if any of emotional involvement, the resources and expectations of his family, his previous education and training, his physical condition and his balance between dependence and independence. Second is the extent that public organizations and agencies in the community provide services to the general population from which the retarded are not excluded by arbitrary fiat or by overt discrimination. Third is the extent to which private organizations and agencies that sanction and operate activities come to incorporate the retarded within their mandates to help individuals with personal interests or problems.

Accordingly, the essential task of the Project as its sponsors defined them were to generate more intensive participation and involvement by the retarded in the existing programs of both public and private agencies, to simulate the development by other organizations of both general and specific programs where none existed and where benefits might accrue to the retarded, to stimulate the provision of direct services that either could stimulate the provision of direct services that either could not or would not be provided by other agencies and organizations, and to improve the scope and depth of the services for the retarded that they and other associations and organizations already provided.

These tasks added up to the aims of the Project: (1) to accelerate any changes that may already have been underway in Bridgeport that would improve the position of the retarded in the community; (2) to weaken or depress any changes that may have been

in process that would either depreciate the lot of the retarded or contribute to the maintenance of what was considered inadequate in the status quo; and (3) to stimulate the retarded's acceptance by those serving normal persons.

In order to assess the changes that the Project actually effected, it is important to assess the changes that are likely to have occurred in services for the retarded of Bridgeport without the existence of the Project. Changes in expectations were occurring during the years prior to the Project and during its life span, and those changes were not limited to the Bridgeport community. They also occurred on the state and national scene, and while the extent and nature of those changes may be debatable and somewhat unclear that they occurred is irrefutable.

A major illustration is the shift in expectations of services from the public school system. In Bridgeport and elsewhere, retarded children were frequently excluded from classes on grounds of being ineducable, unmanageable, or merely limited. In Connecticut as in other states, the right to an education from which the person and society could both benefit was established in the last century. This might conflict with the principle of exclusion of the retarded, as well as of individuals with other handicaps such as blindness, deafness, deformity, on the grounds mentioned or on the grounds that their education would interfere with the education of others.

In Connecticut, the mandatory inclusion of the retarded in the school system was initially sought in the 1950's. Considerable changes in the school careers of retarded children were projected. Bridgeport's public schools initiated classes in 1953; with the first class in New England for the trainable retarded begun earlier, in 1951, at the behest of the Parents and Friends Association. Such pioneering occurred therefore well before the Project was funded.

An overall assessment of change in Bridgeport in provision of public school programs for retarded children was provided (June 19, 1969) by the State Department of Education's Consultant:

There are now (1968) 33 public school special classes for the retarded in Bridgeport; in 1963 there were 31; in 1958, 25. Although there has obviously been growth, it would be difficult to make a justifiable comparison with other areas of the state since some other areas have grown much more rapidly in this respect; others more slowly. I think I could say that growth in Bridgeport in the past 10 years has been about average. There are just too many variables to be taken into account in order to answer these questions in a final way. (Letter from Joseph Lavender, June 19, 1968)

Thus, there is some doubt that the Project effected any fundamental changes in public schooling. Such changes as did occur were well within the normal limits of other areas of the state.

Another critical area of services is rehabilitation, organized under the authority of the Connecticut State Department of Education's Division of Vocational Rehabilitation.

The District Supervisor responded in June, 1968 to an inquiry about services to the retarded by indicating that he felt that acceptance of the retarded in Bridgeport was "about the same", compared with changes in the acceptance of the retarded in other Connecticut communities such as New Haven or Hartford.

He attributed the changes in Bridgeport to "both Parents and Friends and national concern for the retarded. Compulsory education laws for the retarded." This consultant's appraisal of the general acceptance of the retarded "on the job, in the schools, and in social and recreational activities" was "not negative. [They are]... accepted if well diagnosed and properly trained."

Definite changes in rehabilitation services in the Bridgeport area did take place from 1958 to 1963 -- the year the Project began -- and to 1968 -- the year of the Project's completion. Specifically, the District Supervisor stated that the Kennedy Center approached his agency and proposed the addition of a special rehabilitation counselor to the sheltered workshop. Earlier, in 1958, "community groups such as Parents and Friends of the Retarded set up and operated these centers". At that time, diagnosis and pre-vocational training programs for the retarded and their families were underway, because the retarded were rarely suitably placed in employment. Such programs were operated in cooperation with school systems, private industry, recreational authorities, State Training Schools and other Sheltered Workshops.

By 1963, according to this appraisal, some privately sponsored diagnostic evaluation centers were in existence, initiated at the suggestion of "parents organizations." And, by 1968, the rehabilitation counselor mentioned above had been located in the Workshop for the Retarded to provide "added services."

The evolution of rehabilitation services and programs in the span from 1958 to 1963 to 1968 was described in the following terms. In 1958, the rehabilitation services consisted of physical restoration and placement. In 1963, there had been added vocational evaluation and pre-vocational training in Workshops for the retarded. By 1968, the composite of services included as well the provision of extended evaluation periods up to 18 months for vocational evaluation to determine eligibility.

The question is whether the Project itself had any effect on new services. Education and rehabilitation services throughout Connecticut and the United States were changing during the life of the Project, and a judgment of the precise effects in those spheres of the Project must take that context into account. Such a judgment is difficult, but it appears on balance that small gains, none of outstanding worth or of a pathfinding character, were the net result of the effort.

Other areas of services need to be appraised on the basis of general change in Bridgeport, in Connecticut, and in the rest of the country. Whether the changes in Bridgeport have exceeded, kept pace with, or fallen behind the pace of change in other areas remains to be assessed before one may make a definite judgment about the local community. The attempt, however, may be slow, incomplete, or not as comprehensive as the population in need may desire or consider essential.

Several reasons for these inadequacies exist. One is ignorance by the suppliers of services of their neglect of the needs of certain segments of the population. Thus, school officials may at some time simply be unaware of exclusion and discriminatory practices occurring within the systems for which they are responsible. For public education, for example, it is clear that some significant portion of schools have been racially segregated as a result of community discrimination and exclusion, or under-support in certain schools where heavier class and racial imbalance requires in fact additional help.

Second is overt prejudice and discrimination where negative affect colors the extent to which a system accommodates to the needs of a population which it should be serving. In our society, the amount of prejudice and discrimination toward the retarded remains somewhat in doubt, for these human beings do not present the competition, economic or sexual, and status threats which classically lead to prejudice. Nevertheless, inappropriate behavior in common social situations, language limitations, and problems in social relationships with peers may account in a fairly simple form, for prejudice and discrimination on a person-to-person basis. Intellectual shortcomings may be critical as well, given the stress on achievement found within our society.

A third factor in slow or inadequate provision of services may be the extent of resources of funds, manpower, and facilities available to and allotted by public and private agencies. These typically fall far short of amounts necessary for adequate services. When resources must be supplemented or multiplied to be effective, or when special or unusual needs exist, the additions required may simply be unavailable. Prior commitments may already have exhausted existing resources, and, as is well known, the effort to increase the supply of resources, whether manpower, money or facilities, through increases in taxes or in contributions to private agencies, often strikes a stone wall of resistance.

Related to the allocation of resources is the fourth factor, the priorities for service that are determined by (1) ideas of those in occupations and professions that supply services, and (2) the requirements of the systems and organizations where these individuals perform their work. Conceptions of what is professionally proper and of what is occupationally acceptable are built into the world of work roles.

How recruited professionals viewed their work, the Association's efforts and the Project goals, and how their work was organized must be understood in such fashion so we may understand how the Project fared.

CHAPTER VIII

THRUSTS AND TENSIONS IN THE CHANGE PROCESS

The pursuit of change of the Parents Association and the Project it sponsored is a complex phenomenon. This chapter begins with a series of characterizations of the complexities of that effort, provides a broad comparative and theoretical focus for explanation of those characterizations, and identifies modalities of tension associated with the change process.

Characterizations of the Change Process

Eight key points may be made about the change process, as follows:

- (1) The effort toward change was undertaken by individuals grouped into a voluntary association.
- (2) The Association introduced and operated certain programs intended to provide benefits, many previously unavailable, to individuals who confronted discriminatory treatment and prejudice.
- (3) The Association initially acted as a special interest group to induce other agencies, particularly of government but including some private in origin and sponsorship, to change and broaden their programs so as to benefit more extensively the individuals dependent on the Association's members.
- (4) The Association sought to develop an improved integration of its own activities and those of other organizations, in part by obtaining, where appropriate to existing priorities and mandates, the allocation of resources from outside organizations to the sponsors' programs, in part by projected cooperative efforts with such organizations, and in part by provision or assignment of staff aid or consultation to the other organizations.
- (5) The Association sought to improve its own efforts and those of other organizations by hiring professionals and other employees as Association staff members to implement the Association's goals.
- (6) The Association applied for and obtained a large grant of federal funds to support a five-year Project to "demonstrate community-based services for the retarded."
- (7) These several efforts toward change, including the Project, entailed
 - (a) moments of crisis significant in the affairs of the Association,

(b) periods of difficulty, of crisis and trauma, in the relationships between, first, staff members and leaders of the Project, and second, the Board and membership of the Association, and among Project personnel themselves,

(c) discontinuities in continuing relationships between the Association and other organizations, and

(d) alterations including discontinuities in the pursuit of change undertaken by the Association through the Project, a restriction of effort to a few areas of change rather than maintenance of the broad program of change to which the Project was initially committed, and a relatively frequent though not universal tendency to refocus the attention of those engaged in the change effort from target to target in a fashion that implied a disruption or non-planfulness of the overall effort.

8. The thrust toward change in Bridgeport included tensions in the Association, in the Project, and in relations between these two and other organizations and agencies.

These descriptions of the pursuit of change must be placed in a theoretical context for their full explanation. Dedicated agents of change engage in its pursuit with fervor but often, it would appear, without a full appreciation of the nature of events or the settings within which they act. A comparative view of organizational change and efforts toward that end will clarify the occurrences of change and permit, it may be hoped, their better explanation. For such an explanation, characterizations of organizations, of their structures, of their relations with the relevant environments, and of the manners in which changes are undertaken, are essential. To this we now turn.

Comparative and Theoretical Focus

The search for change in the efforts of organizations entails redirections of effort and of values and thereby brings into action a complex array of behaviors by those pursuing change and by the targets for these efforts. Dedicated pursuers of change plan strategies based on (1) their conceptions of the need to reduce the gap between expectations and reality, and (2) the resources they command, and (3) the points of entry at which they believe results will follow effort.

Efforts toward change may be directed at organizations within which those espousing change may be a functional part. Possibilities here include managers or owners at the top of the status system of vertically structured organizations, college deans and professors in academic systems, or executives of professional associations, and their efforts may focus on improvements in internal communication systems or decision making. Or, efforts may originate at the bottom, when, for example, numerous individuals with little status and in receipt of limited rewards, strike or protest in diverse ways about their minimal independence, lack of control or scarce rewards for effort. Middle level personnel may also desire change, such as improvements in financial or other rewards, increased freedom improved promotional opportunities, or greater recognition.

The stability of an organization and its response to such change efforts are affected by the perceived legitimacy attributed to those espousing change. Efforts toward change may be seen as desirable but untimely and thereby inappropriate, possibly premature in view of the attitudes and capabilities of those who must contribute to the change or be subject to it. The combination of legitimacy and timeliness occurs but the absence of either element can be frequently noted.

Expectations may be negative toward roles whose incumbents see the pursuit of change as appropriate and timely. When the "wrong" people pursue change, responses may encompass the belief that the pursuers of change are acting inappropriately and illegitimately, possibly wasting time by not meeting the essential obligations of their roles.

Organizations that are targets for change may be small or large, new or old. Both new and small organizations are often thought to be particularly amenable to change processes. Neither procedures or roles may be well established, and the inexperience of staff may make them particularly susceptible to suggestions and open to models for the alteration of their behaviors. Yet, close communication and systems of personal relationships encompassing a wide range of work behavior are not universally found in large or old organizations. Anonymity and physical or social separation of role players found in such organizations may permit change. Reduction in the visibility of efforts may leave room for change that can be unknown to various elements in the system.

New and small organizations may further be constrained by well-established models for their organizations. A surgical unit, a post office, and an air controllers' tower may be forced into molds established by practice and by fiat that ordinarily leave little room for innovation by those who work within them.

Change may be pursued by those peripheral to the organizations which are the target. Outsiders become dissatisfied with the nature or extent of work performed or services provided, and seek improvement. They may desire to enter into organizations to participate more effectively, to control its activities, to change its work pattern, inputs or outputs, or to acquire in some fashion a share in benefits that membership or employment may yield. Outsiders may conceivably wish to reduce the scope of activities and services of organizations whose basic legitimacy they question.

Insiders to an organization may seek to change its relationships with other organizations within which the actors also maintain some role. A mixed strategy may occur, involving an agenda for change in internal allocations of resources or of goals as well as an agenda of change in relations with other organizations. Conceivably insiders may wish to redirect the activities of other organizations, using the platform of their prime organizational involvement as the hoped-for legitimator of the effort.

Such platforms in fact vary in the legitimacy and sanction they provide for change. Membership in a polity provides a legitimate base for seeking change in a government through voting and the representational system or by lobbying. Union membership has come to furnish a legitimate base for certain changes in resources allocations by employers, such as wages, welfare benefits, and hours required of employees. Student roles provide controversial legitimacy for affecting faculty policies and, in the views of certain more activist elements, a base for political action and community change. Clients for organizations may seek to change them,

such as poor parents seeking to alter school curricula and administration or the scope of services of health and welfare organizations. Customers eschew picketing of merchants with pricing policies to which they object and affect them indirectly through market mechanisms. Special organizations of consumers, consumer cooperatives, do in fact set pricing policies, and picketing for credit privileges to be granted by merchants has been undertaken by members of associations of those receiving public welfare.

The conceptions of what needs to be changed may take the form of a utopia where problems disappear and tensions vanish. Such broad-scale visions often accompany intense motivations and activist orientations among those accepting them. Impatience with what others conceive as established reality features such dedication to the pursuit of change. Agendas for change associated with such utopias are extensive, though segments of the lengthy agendas may be covert, possibly even unclarified or unformulated. In contrast, to utopian conceptions, formulations of change may be specific to particular organizations, involving merely a shift in procedures or changes in actions. Pursuers of change may adopt or follow mixed strategies that include both utopian conceptions and specific formulations, and shift from one to the other as various efforts yield success or failure.

The sustaining of effort toward change through an extensive period of time is unlikely. Failures or partial successes in early efforts dampen effort, and partial success may in event satisfy some initial proponents of large-scale change. Utopian visions compared with existing or somewhat altered practices of contemporary organizations prove illusory, hence discouraging to many. Concentration of attention and investment of energy on targets for change dilute in the face of other activities that compete in perceived interest or satisfaction. Active resistance to change may mount as well as diversion, or subversion of those oriented change. A lengthy program of change may be supported, but the succession of cohorts of supporters and proponents can weaken the continuity of enthusiasm, dedication and effort. Periods of feverish activity by coalesced individuals dedicated to change precede periods of isolated activities by dispersed actors with few items on a common agenda.

In the course of the five year Project to change community services for the retarded, in Bridgeport, the host of occurrences demonstrated many of these points. We turn now to these events and to the tensions that occurred in association with the change process.

Tensions Affecting the Change Process

Several recurrent fundamental points of tension have marked the life span of the Project and the efforts to accomplish its purposes. One critical point has been the definition of the roles of the Project staff. This may be broken down for the sake of convenience into (1) the role of Project Director in relation to the expectations of the Board members and parents, and (2) the roles of professional and other staff members recruited for the Project, again in relation to Board members and parent members of the Association.

It must be said at the outset that these roles and the expectations of Board and Association members did not entail a simple set of confrontations. The issues have varied too much for this to be seen only as a "we-they" clash or an insider-outsider conflict. The patterning of these roles has involved, the activities of a changing number of parent-

participants concerned about the welfare of their children or relatives, who have organized into an association better to provide or obtain resources for their children. Seeking to improve such resources, they sought over the years to engage other agencies in the provision of services and to provide certain services on their own. Change in community resources was and is their aim; the Project was their agency, along with other methods such as studying and supporting legislation, and other forms of persuasion and pressure.

Change in resources, however, is not readily measured. "We want more" is not a clear-cut formulation of priorities, and achievements, no matter how noteworthy, always fall short of the expectations of many participants.

For the Parents and Friends, the buildings first on William Street and then on Virginia Avenue, were major physical manifestations of success. These were settings for many programs highly desired by parents. Similarly, award of the grant for the Project was a major achievement, heralding their past success and the potential for solidification of those successes as well as the promise of newer developments.

What the other detailed program changes were precisely to be, what images of the future existed at the time - these were left unstated in the rosy glow of accomplishment. It appears in retrospect, that the improvements expected were not clearly stated, that the pursuit of change was itself taken for granted as a value, that priorities for change and the allocation of resources in terms of such priorities were left unclarified. Conflicts in expectations and in roles could readily occur as a result.

The pursuit of change and the tensions associated with it may best be understood in terms of the phenomenon of sponsors and implementers. In the history of the Parents and Friends Association, various key leaders have been frequently described by observers and participants alike as critical in its affairs. These leaders have served, in a sense, as heroes for the Association's members and its Board. Heroic portrayals of the roles of Eric Sandahl, Bernie Green and Evelyn Kennedy come to mind, as do those of Maury Mezoff, Warren Faust, Stanley Meyers and Bernice Vennert. These individuals have been described by various persons as dynamic or vital personalities. It is noteworthy that there has been a succession of such heroic leaders in the affairs of the Association, of its Project and of its programs; these persons have in diverse ways shaped and directed many courses of action during the last several years.

Mr. Sandahl and Mrs. Kennedy, both parents of retarded children, were in at the beginning, during the ferment of ideas, efforts and achievements that marked the early years of the group in the 1950's. These people were directly involved in leading the efforts for the buildings. A lawyer in Bridgeport, Mr. Green began to play a vital role in local and state leadership a bit later. These three were directly involved in leading the efforts for the building programs.

Mr. Meyers is seen by many in two lights: first as an early Association director who worked closely with the parents, and second as a returning Project Director - Association executive who helped pick up the continuity of the Project at a later critical point. The initial Project Director, Mr. Mezoff is seen by many as a hero who dominated and drove the Project once it began but who fell from that key position in the big crisis in the Pro-

ject in 1965.¹

Before that time, Mr. Sandahl had, in effect, withdrawn from local involvement, as his locus of effort shifted to Hartford. Mr. Faust, an industrialist in Bridgeport, was an early friend of the Association during the 1950's, and placed his support more directly behind the Association in the 1960's. Through his involvement and interest in residential homes and as Treasurer of the Association, he served as financial bulwark in the period from 1965 to the present. Miss Vennert has been identified by many as a vital program operator who provided services unavailable through any other means for those thought to be neglected by the schools, state center and other agencies. She was especially identified in 1967 and 1968 with the Tri-Us program of the Association.

Certain of these individuals have gone through cycles of approval and disapproval as the affairs of the Association and its Project have flourished or weakened in the view of Association participants or observers. It is noteworthy that changes in the identification of such heroes are basic to an understanding of the organizational changes that have occurred. Interviewers have agreed in general that the phases of change -- association-run programs, the building phase, the Project phase, crisis and consolidation -- have been marked by changing heroes.

The definitions of such resources as parents and professional staff have also changed in relation to these phases. At various times, parents characterized professionals as "critical and necessary", "objective", "outstanding", "disinterested", "unappreciative", "outsiders" and "unemotional". Professionals have defined parents in turn as "sincere", "emotional", "fighters", "destructive", and "selfish". Professionals were seen by some as working full time but in an unemotional way on tasks defined for them by parents who have a deep personal problem. "They work for us" was a statement about professionals expressed by a number of parents.

This generates opportunities for disagreements in the definition of roles. An illustrative criticism was expressed by one key staff member who stated that "parents did not like the expansion of the roster at the workshop to include new clients who were outsiders." (11/14/68) The expansion itself was attributed by certain parents to the professionals.

A formulation by a staff member highlighted another problem, stated as well by others:

One unique theory made it difficult. The person receiving service was the employer of the professionals. They denied some of their own problems. Some people were active in the organization...to find their own solution to their problems by getting involved in the building program. The professionals did not want to stand still. (9/12/68)

¹ The crisis is referred to at various subsequent points in this chapter and elsewhere in this monograph. An extensive account was prepared as the body of the July 1966 Progress Report for this Project and is reproduced in Appendix V below.

One issue was whether new or enhanced services were aimed mainly at Association members and their relatives or were to serve all in the community who needed such help regardless of membership. Another issue concerned whether the Association itself should develop if possible all its services to the maximum needed or encourage other agencies where possible to engage in the effort.

The issues were expressed by an observer in the community who stated:

....they kept everything within their own group and didn't involve others who had some involvement with the mentally retarded. The first mistake was not contacting other agencies to find out what was being provided.... They knew all the answers.... There were signs of empire building. They were like other agencies who come in to attempt to set up programs without consulting existing agencies. (9/17/68)

A key parent commenting on the specific item of the recreation program at the Y observed that continuity in effort was minimal:

We failed as we did not get to other schools outside of Fairfield and Trumbull. I felt more follow-up was needed. No one gave directions to the Y. Continuing follow-up did not occur.

The lack of expansion and continuation of effort hampered the Project's long range plan.

What seems in retrospect to be a major area of early Association achievement was its construction of two buildings in Bridgeport to house programs for the retarded. These efforts involved fund raising campaigns that may appropriately be described as herculean for a voluntary association of parents and served for a period of ten years to dramatize effectively the nature of their large accomplishments in the accumulation of resources. The burdens of effort and of internal dissension proved nonetheless to be substantial and to have impact for the later Project.

The first building, on William Street, was erected in 1955 and 1956 as a community center for the retarded. Land was purchased, and then an estimated 70% of the necessary labor was carried out by parents of the Association. Beginning in 1956, diverse programs were undertaken, including the creation of a diagnostic clinic, pre-school, junior day-care, senior day-care, vocational rehabilitation, and speech therapy, plus a variety of evening programs.

Judging that the facilities had become inadequate, the Association began in the early 1960's to plan for the construction of a new building, to be known as the Kennedy Center. Some 16,000 square feet in size compared with 3,600 square feet in the original structure, the building was designed by an architect to serve 250 children and adults. A "...modular type corridorless design allows for a very flexible use of the building... All services and programs of the agency will be located in a single building. [It] will be the first known

community center in the country to be specifically designed to meet the total known needs of the retarded."²

The large facility was expected to cost \$400,000 with equipment and to be funded in part by a \$100,000 Hill-Burton grant from the Public Health Service.

Opened in 1964 by the Association, the building was turned over to the State of Connecticut one year later. This event was recently described as follows:

...members of Parents and Friends in an unprecedented action, voted to make an outright gift of this newly-opened building in order that state-sponsored services might be available to the children of this area at least two years sooner than would otherwise have been possible.³

At present in 1969, the building houses the State Regional Center for the Retarded.

The efforts of the Association reached a high point in the construction effort. As one speaker recalled,

We had big community backing when we demonstrated the need for a building at William Street. We got publicity. And then the city administration gave us the site for the new building for a dollar a year. With the dedication of the Virginia Avenue building, the community saw what we were doing and they gave us support. Once the building was put up, the United Fund began to give support. With the building up and operating, until the state came in, there was much that was positive.

We had a reputation second to none as an agency that worked for ourselves. ...Everyone was willing to help.

And a staff member added:

The parents felt they needed something unique to stand out in the United States. This building was to be the prototype for all Regional Centers in Connecticut, covering day-care and residential services. The building was designed as a prototype with the internal structure set up so it could be used for residential care or day-care.

² From Project Proposal, quoted in full as Appendix III below.

³ From a 1968 history of the Association, quoted in full in Appendix VI below.

But Parents and Friends never contemplated their building as a residential center; they did contemplate making the design available as a prototype. ... The biggest thing Parents and Friends had was the building.

Given the pioneering character of the effort, the first of its kind in beliefs of those involved, and with no model to follow in its evolution, the building design and the construction effort were unusual. Programs to use the space adequately and the building design itself could have been more adequately coordinated.

Highly positive and highly negative statements about the building structure and the efforts of the Association at this time continue to be made. The crescendo of effort clearly engaged the energy and attention of many people to the full and strained the organization. As one speaker noted,

They miraculously raised \$300,000 for the building and could not meet the last \$75,000 to cover their operating budget. ... If they could have operated it, the state would not have come in as the Regional Center.

The buildings on William Street and later on Virginia Avenue are seen either as monuments or as millstones by different speakers. While some felt the buildings were distinctive achievements of the Association of parents who were thereby demonstrating leadership in both state and nation, others evaluated the buildings as burdens or in other negative terms. Some examples drawn from three interviews in 1968 follow:

Some people were in the organization to escape from their own problems. They found their own solution by putting up that building, [The Kennedy Center building on Virginia Avenue], and the professionals didn't want to stand still.

One thing that parents were unhappy about was that the [Virginia Avenue] building was finished, the workshop was in it for no time and there was not enough room and they couldn't carry out the business of the workshop. They had to move and many parents were upset. We took a lease at Bunnell Street; the problem of transportation was compounded....

[The building] was a real lemon on our hands. The renovations show it was poorly constructed. We were glad to get rid of it. The take-over was one of our biggest feats. It's a perfect example of what the Project set out to do, to get the State to assume responsibility.

[The building] was a white elephant.

Such characterizations do not detract from the comment of an early proponent of its construction that "...the building had a beauty and integrity of design."

The second construction effort, the operation of the building by the Association in 1964 and 1965, and the transfer to the State, provided a hectic setting for the Project which

began in 1963.

Project Organization

The complexities of events, problems, situations and programs hinder a simple understanding of the Project. Structural anomalies and operational conflicts existed. Review of these must begin with a recapitulation of the earliest period of the Project. In recollection of this, various participants frequently shifted back and forth from Project to Association during their discussion. One key person, prominent in the affairs of the Association and in the state, commented on the early thrust of the Association in response to a question about the Project, as follows:

People look back to the crusading time, ...there's a lot of emotion. The momentum could not continue. A lot of steam disappeared. In Bridgeport, the Parents and Friends had the highest rate of participation of all cities in Connecticut. They had a zest, a drive, a chemistry, that's hard to define. It was the right group of parents getting together at a certain moment in history, but it was self-defeating because you could not expect the parents to sustain these efforts. (9/19/68)

Such a thrust was powerful, although events later deflected its direction and dampened its force. A combination of internal organizational problems, the dispersion of interest among members as particular programs attracted support or proved disappointing, community resistance or apathy, and difficulties in dealing with staff, served to reduce the Project's success in moving toward its goals.

The Project-Association-Center complex could not easily be separated into component elements. One staff member commented on this point as follows:

You can't divorce the Project from the association, I don't believe there ever was a Project. It never existed as a separate entity. Some people visualized it as paying the bills for on-going programs and developing new ones.... The fundamental aim was to get the community to keep the retarded and to use their own services as a base.

But they did accomplish the purposes of the Project, whether they realize it or not. The money actually accomplished the purposes in the proposal. They have a Regional Center, day services by the Regional Center and by Dr. Dinan's Health Department, a potential for assimilating the vocationally trained retarded. If there was no Project money, the agency would not have been forced to look outside and would have kept its own services in competition with others. They did not keep the camp; they have the workshop but would not have discussed amalgamation, and they would have kept the clinic because they always had a clinic. By the Project having money, the state was forced

to go faster on some things. (10/12/68)

The issues expressed here reflect the difficulty of isolating Project from Association and Center. This was a difficulty in many of the comments of the individuals interviewed, and in the retrospective analysis of the Project's activities by the Project Writing Staff. It does appear that many particular events and specialized programs of the Association were justified on the basis of the Project and subsumed in the thinking of many under broad categories in the Proposal.

Another point is the variation in the definition of "success" and "failure" among those contacted. Disentangling Association goals, parents' satisfaction about gains in their children's behavior, and Project goals in recruiting staff and in broadening community involvement with the retarded, often proved virtually impossible.

The complicated intertwining of Project, Center, and Association affected the Association's position in the community. One key parent observed:

There was a change of image in the community because of the grant. We had a reputation second to none as the agency that worked things out for themselves. With the grant, they thought we had all the money we needed, and we moved our offices to Commerce Park, and there was so much publicity because of the professionals, and the whole feeling coming in was that the Kennedy Center no longer needed as much help. The grant really was our downfall, as the Parents and Friends lost support. Community interest was lost in a sense with the state coming in. Some donors were most upset. Why do you need help? (6/10/68)

One significant internal issue concerned the Project's location and address. As one active participant stated:

There was strong feeling. Some felt the Project should be under the Virginia Avenue roof, the Project belonged to Parents and Friends who had the final say so. Another school felt the Project would be better off if it was in a different location as its business was different.

The [Kennedy] Center was involved with children and the Project did not deal with children. I never thought that was their purpose. I constantly heard people say, what are they doing for our own kids?

I would try to explain we have to have people go out to try to get others to do things that are already in the community so we don't have to duplicate. I can hear Mary Switzer say, try to make the mentally retarded as much a part of the community as possible.

You can't expect someone working constantly with children to visit other agencies and make contacts.... The Project recognized the need of the parents to be involved. We'd moved a mountain but we didn't see others doing it. I had respect for professionals and

their proposals.

Thus, Project and Association were tied closely together in the thinking of many parents. Other comments along these lines confirm the point that, for many in Bridgeport, any independent and non-service activities of the Project were not fully understood or appreciated by many parent members of the Association.

Looking back to the early events of the Project, one observer commented.

[The Director] wanted to strengthen the parents' activities as the first step prior to getting other agencies to act. They needed a high quality of service by the parents in order to change current services which needed enrichment in quality. He felt Bridgeport parents had little knowledge of what others were doing. They had been rejected. He started a survey of resources: this was the goal of the Project. He was a community man and saw great potential untouched.

But [they] never got to the community. They never got the main responsibility--public education. There's the big difference between a voluntary agency and a parents agency. Family Service for example fills a definite role. When an agency like Parents and Friends come along with a variety of programs, and they're supposed to demonstrate, they can't possibly do it alone. I think they never accepted their demonstration role.

...The Project came to envelop the Association. You couldn't figure out where the Project was in relation to the entire Kennedy Center.

On public education, that's true of all parent organizations. (5/10/68)

The problem of directing effort by staff members of the Project to Project goals, as well as to the many-faceted Association goals, does loom large in the reports of many participants and observers. Yet the fundamental commitment of the Project to community change was assumed through the very establishment of the Project by an association trying to cope with agencies of government. These difficulties of the mechanism of the Project must not be minimized.

The interaction of Project and the Kennedy Center was, at best, complicated. In the thinking of some, the Project did not exist as a separate entity; it was mainly viewed as providing the means for the Association and the Center to accomplish their goals more effectively and perhaps on a grander scale. One observer stated:

....the Project staff and the Center never get together. The trouble was that [one executive] felt he knew more than the parents and did not adjust or change his behavior. This was the reason for confusion between the Project and the activities of the Association. A big problem in a parents association is to get the volunteers to an understand-

ing of the professionals' roles and visa versa. I never felt the role of the Association staff and executives was accepted. There was little understanding of the research and demonstration aspect of this Project.
(6/21/68)

Added to the inability to separate Project from Center or Association was the intruding factor, according to a participant, of growth. He expressed it as follows:

It gets more impersonal, bigger, and more complicated. Parents didn't like the counselors who were brought in. Distance gets greater. The rigid relationships--we were never used to this, and we could not take new authority relationships.

The organization of the additional staff that was recruited for the Project and their patterns of work of these individuals thereby compounded their reactions to the Project. People active in a close-knit system of personal relationships found strangers in their midst as partners in the pursuit of change.

Another complicating occurrence was the greater involvement with government, toward which many parents were predisposed by experience to be ambivalent. On the one hand, state employees were viewed as slothful and neglectful of the retarded, while on the other their participation was deemed vital to the enhanced activities of the Association. Thus, an association pursuing change in the treatment accorded its clientele or their dependents provided by agencies in effect both disliked the agencies and became dependent on them for change.

In addition to the ambivalence in attitude, an organizational problem existed in the attempt by a private group to influence public policy. The significance of this may be highlighted by the comment of a national leader in mental retardation services who observed that in Bridgeport

...the problem was a voluntary parent organization taking on the assignment of trying to coordinate governmental agencies, such as the schools, and whatever.

...This simply doesn't work. It is simply not possible for government agencies that aren't coordinated with each other to reach coordination with or throughout the sponsorship of a voluntary organization, parents or otherwise. (5/1/68)

This problem was to influence the Project throughout its life. Both successes and failures occurred.

The Programs of the Project

Diverse and complicated programs were envisioned for the Project in the Proposal which the Association prepared in its grant application. These are analyzed elsewhere in this monograph. Here is undertaken an analysis of the overall effort directed at this program. The ef-

fort to further them and to combine them effectively with the existing activities of the Association and of other organizations in the community was the major aim for the Project. The focus in this section is the programs and their relationship with the community, viewed as a process of change.

Problems existed in understanding the aims of the Project's programs. According to one informed participant, the premise of the Project

... was to go into the community and do away with duplication of service. For example, if the Y was giving swimming lessons for the young, we'd see if the retarded could be included. We'd initially supply staff, help train the staff, and then eventually the program would be self-sustaining. The Project would pull out. The star example was the Y.

The Project, [said another parent], ... was to have extra money to do the things we wanted to do... We had day care, programs for the severely retarded, but.... this would open new doors and let us have a new staff to expand in all these directions we could not do on our own. It turned out we used the Project for operating and did not do what we should have done. (9/18/68)

The aims of the Project as seen by a former executive of the Association were, in this view, not really understood by the Association or the Board.

I feel the general premise was never understood by the Board or the membership. They had provided their own services as a vested interest group. The majority had an anti-professional feeling. You just had to be warm and love the retarded. Some were ready to move in new directions and some were not. Many said let's go back to the old days, that we lost the warmth and intimacy of those days.

Basically, they're still for the same group of youngsters with whom they started. I saw the Project as an opportunity to move to new youngsters on the fringe. The organization started with those needing custodial care; with the Project we saw an opportunity to prove new services that would eventually be taken over by others. We were most successful with the Y in Fairfield. We worked hard on the special program for the Fairfield and Trumbull schools for the trainable. The Project initiated this, to balance the day, and permit socializing with peers. The Project donated money to the local Y and enlisted the aid of the state. It started as a ten week program at the end of the school year.

Now we're very proud of it. We hoped to extend this to Stratford and Bridgeport, but we did not.

These comments highlight the difficulty that confronted the Project in engaging itself

with the community generally, given its fundamental sponsorship by a private association oriented toward services for its own membership. The Project's mandate was to serve the entire community through the generation of varied new services. Its efforts in those directions continued at a varied pace throughout.

Some indications of the community focus, and the problems this entailed, were expressed as follows:

We started to do a lot for the community; we helped get ABCD started. Several people were involved: the Director, Bernie Green and Eric Sandahl.

We did a survey of all the special education students and developed a decentralization plan to avoid long travel and keep the community support. [The Stratford satellite workshop was mentioned here as a prototype.] Many special education graduates would go to the sheltered workshop. DVR would help carry the budget. We were tying the program in with the schools, with a half day in the third year at the workshop.

A conflict developed, because people said, you're letting strange kids in, not ours. ...They could not accept not running their own services.
(9/10/68)

The ambivalence toward outsiders was reported by the alleged frequent question, "what are we doing for our own kids?" "They're hiring more staff and they're not doing more for our own kids." One parent stated, "we've never used professionals up to their potential."

The issue posed by outsiders was implied in the choice between continuing to operate service programs for one's own membership or releasing demonstration programs to other agencies. This proved to be a complex problem. Participation of new members and continuation of old members' support of an association of individuals who participate as volunteers may rise or fall depending on what benefits members see accruing to them due to membership. The more programs exist, the more the need for them is felt and the greater the intensity and extent of participation. Loss of programs thought to benefit the volunteers may lead to apathy and withdrawal.

Programs, however, do not exist in a vacuum. Resources for their continuation may be beyond, or be seen as beyond, the capabilities of a single group. In this instance, the problem of choice outlined above has been an acute one. This was viewed by one individual outside the association in vivid and empathic terms:

When an agency like the Parents and Friends has a variety of programs, they're supposed to demonstrate with them. They can't possibly do it alone. I think the Board never accepted their demonstration role. They thought they were in the business for life.

They were reluctant to give up the building but it was a marvelous opportunity. They've been rejected and don't trust anyone. Actually they're forgotten more than they're rejected. (5/10/68)

In this particular instance, various factors compounded the problems confronting the Project and the Association. As one parent put it,

Many of us felt we lost the image we had in the community because of the grant. People felt we were getting all the money we wanted. We had plush offices, and the staff turnover hurt us. It was bad publicity in the press and the talk was that we should have done more with the money.

The commitment of the Project, expressed in the grant proposal, to move out into the community, led to internal stress. One observer of this expressed it as follows:

[The Project Director] wanted to strengthen the parents' activities as the first step prior to getting other agencies to act. They needed a high quality of service by the parents and to change their current services to do this. They needed an enrichment of quality.

[It was felt that] ... Bridgeport parents had very little knowledge of what other agencies were doing. No one had the professional skill to find out what they were doing or how to find out, either for private or governmental agencies.

They had been rejected. [The Director] ... started a survey of resources. They were upset about outside help until he came along. They did not trust outsiders.

One problem with [the Director] was he moved into the community. He saw great potential untouched. They caught the imagination of the community but did not follow through. But the leadership was ingrown and this was not conducive to getting out into the community.
(5/10/68)

These interplays between enhancing the concern and involvement of existing agencies in the community and maintaining the effort and activity of the sponsors of the Project clearly rested on diverse conceptions of what was appropriate role behavior for Project staff, the Project Director, the Board members and parents.

The roles have been subject to re-definition and points of stress at many times through the life of the Project.

The Project, [said a parent], ... was to have extra money to do the things we wanted to do.... We had day care, programs for the severely retarded, but.... this would open new doors and let us have a new staff to expand in all these directions we could not do on our own. It turned out we used the Project for operating and did not do what we should have done. (9/18/68)

It appears then that the outside staff was viewed by the parents as implementers of their goals. Given this, the parents wanted workers to carry out the parents' wishes and objectives; they did not view professionals as persons likely to have independent perspectives that could lead to the re-defining of the Project goals.

One individual with administrative responsibility commented as follows on the parents perspectives dealing with public responsibility inherent upon the acceptance of the grant:

Parents and Friends could not accept or understand the responsibility they assumed to serve the public and the accountability for public funds associated with the Project grant from Health, Education and Welfare. There were exceptions. The Association's President did and so did ...[one of the Board members] at least partially.

On the workshop in Stratford, the parents were very ambivalent that other people, not members, would be served, though this was the conception of the Project. They visualized this as our money to do whatever we wanted or had to pay for. ... There was a great deal of resentment about the expansion of the roster at the Stratford workshop.

And at the Y, certain parents felt that outsiders would be caring for our children. ... They were very ambivalent, but we got it accepted and then they kept on with their own program.

[We] ...needed help... to make sure the Association met its financial obligations to the state and federal public agencies and to the United Fund.

The basic ideas were that we're the pioneers and crusaders and now we're going out into the community, and that the professionals are bad boys and are trying to take over.

Overall, the potential for the Project was diminished by parent self-interest, seen here as an impediment to change although identified elsewhere, and at least by many parents, as a powerful generator of change. The negative view is here expressed as follows:

I saw great potential in the Project, I could envision so many doors for so many youngsters,for those stumbling through high schools. We never really had an opportunity for follow-up. There was also a great need for family counseling.

So many things had just about begun in 1965 and we were beginning to move. I spent so much time with the Project and there was a constant involvement, five or six days a week. ...Most parents were interested only in their own child. ...We couldn't get anyone out to the general meeting. Parents and Friends meetings were always

small. The night the general membership voted to turn over the building [to the state] I don't think there were fifty people there.

The issue of the breath of composition of those served and their potential inclusion in Project-aided services was related to roles. It was expressed by an observer in the community who stated:

.....they kept everything within their own group and didn't involve others who had some involvement with the mentally retarded. The first mistake was not contacting other agencies to find out what was being provided... They knew all the answers....There were signs of empire building. They were like other agencies who come in to attempt to set up programs without consulting existing agencies.
(9/17/68)

A key parent commenting on the recreational program at the Y observed that continuity in effort to other communities was minimal.

We failed as we did not get to other schools outside of Trumbull and Fairfield. I felt more follow-up was needed. No one gave directions to the Y. Continuing follow-up did not occur. [The Project Director]...was great in getting things started but then we always seemed to lose out...Communication between the Y and the schools broke down. We should have been there assisting... (9/18/68)

Related to this was a tendency by certain staff members to conform to traditional role patterns. This was explained by a former Project Director as follows:

I told the clinic director of the need for community services for at least one day a week when he should spend time with other agencies. He was clinically trained, and believed the clinic should be in charge of all services and outline an individual program for each person getting services from any unit.

I tried to explain that we're dealing with thousands of people and the clinic supervision for each one was not possible, that the clinic must be a handmaiden....to other services in an adjunctive role to more important rehabilitative functions. [Social service] and [the Clinic Director] ...pushed for the clinic.

I had to show them the community. They'd never been to the agencies. I was anxious to develop relations with other agencies and get us involved.

These problems involved the internal coordination of programs and units of the Project and their articulation with pre-existing segments of the sponsoring Association. In summary of the community involvement of the Project and its programs, one individual noted:

There was no follow up on clients even during my time. This was a great lack. The number of cases that confronted us was extremely great on the limited amount of time we had. This brought us into conflict with the parents. There was no opportunity for longitudinal evaluations. They were intent on servicing all cases, you could not close down input.

Concerning the Project per se, he stated:

...it represented an umbrella that represented everything at the Kennedy Center.... From a research point of view, the proposal was horrendous. For delineating procedures, it was mainly emotionally tinged words. I appreciate that demonstration is different from an experiment, but nevertheless I don't think it was research. (6/13/68)

These negative words present criticisms in a rather gross fashion but it should be noted that the ideas expressed and the themes voiced are paralleled by the comments made by others.

For some parents, the Project was seen as creating growth in staff and the hiring of professionals who did not understand their point of view and consequently threatened to take over control. The transitions were seen by some influential parents still active in the Association as questioning control of the Board composed largely of parents. "The professionals felt was wrong... what they admired at first," that is, the active involvement of parents, according to one participant's statement. (4/27/68)

The Project staff and office with many busy professionals was described vividly by a number of Association members as too impersonal. One reported this and another element of concern in saying that

We felt the Project was becoming big business. We saw the high salaries being paid, and we had raised lots of money but it was for the building and the kids. We couldn't see the justice of high salaries.

Another reported that:

My first impression of the Project was that it was to have extra money to do things we wanted to do. We had day care programs for the severely retarded, but to me this Project would open new doors, and let us hire staff to expand in all directions we could not do on our own. ...It turned out we didn't do what we should have done.

The big successes of the Project were the camp, the Fairfield Y, and the Visiting Nurses association.... But in the last couple of years, the Project did very little.

So much more could have been done, especially in pilot projects, even with the state coming in. ...People said, they're hiring more staff

and we're not doing more for our own kids.

...In recent years of the Project, frankly very little was accomplished. [The Director] inherited great problems, and he did not have as much support as he would like.

We never used the professionals up to their potential. We should have professionals at meetings and use their knowledge. Most of us feel professionals should live with us for a week and get some real feeling. There are always some who say, the parents don't want to let go, they want to be involved. Many times, we're too ingrown, but this was the time to get things done at Kennedy Center. We felt we ought to concentrate.

A continuous problem centered on the relationships between the new state Regional Center and the Project Association. It was expressed by one informed participant this way:

With the Regional Center coming in, I wanted its services to take over and the Parents and Friends to keep going in public relations, work with the legislature and fund raising. We would experiment with new roles for the parents.

This involved not simply the question of whether a state agency was taking over efforts initiated by the association. It also reflected the apparent ambivalence existing among parents regarding the transfer of activities to outside organizations of any character.

A description of the diverse pulls and pushes was phrased as follows:

They wanted to recapture services, even when they were giving the building away, and recreation was another area.... The in-group wanted to run their own programs for their own kids. The Y was taking over recreation and then they went ahead with their own program anyway for their own kids. Goodwill wanted to take over the workshop, but they wanted their own workshop.

The Project's program efforts and accomplishments were summarized by an active participant as follows:

It got us Tri-Us. This shows it can be done. It put Parents and Friends in the big league. But there was an abrasion and diminution of our reputation. We did something for the state, by pressures of them.

But it did not accomplish the goals set out for it. It did not follow the plan. ...From 1966 on, there was no attempt to inventory possible new relationships with agencies or services with which the Parents and Friends could develop links. ...The aim was to forge new relationships, not to underwrite a series of sub-projects, and no one has made a list. I don't think the record is impressive. You can't des-

cribe the second half as a demonstration of what was intended in the Proposal.

A big failure was intensive day care; it folded quickly, as the cost of transportation was too much, and the decentralized day care idea to be tried in Trumbull was also a failure; not enough kids were in it. (9/19/68)

On the specific clinical program of the association and its involvement with the community, one observer commented:

To be honest, speech and hearing was by itself, alone. There was very little interchange with the Rehabilitation Center. It had a big waiting list. Personalities were involved very often.

It was difficult for any ...professional to remain with the parents groups, they made so many demands.

I can't think of any real interchange with the community. We did everything, we had our own doctor.

The point stressed was that retention of services predominated over extension of programs in the community.

How the Project itself fared was reviewed by one speaker, as follows:

It was a segmented operation. To be frank, there were separate small groups who did not explain themselves to others and they did not care what other groups thought or were doing. There was a lack of cohesion. My one question is: show me what was done for the mentally retarded?

Parents and Friends kept at a layman-agitational level, even with all their gains. I admire them greatly for this, but not letting go was a failure. If you ask what the Project did for the kids, I think it was a failure. At the level of change of attitudes in the community, I think it was more successful. The retarded are not scary anymore, and maybe this was due to the Parents and Friends. They agitated as laymen to get something done; if they had not done it, nothing would have been done. The professionals would not have moved. They should have agitated more with the professionals and with the state. When they got support, they said they needed the Project. They should have stopped being laymen and agitators and turned things over, and removed themselves as lay people who had made the need known. They no longer should have a control role. Here they fell down by keeping control over professional roles. They should have let the professionals run it and kept going as external agitators.

I don't think the program was constructive but I think the programs at the public agencies fail even worse. It's distressing there was so much effort and you get so little return, but much was done. I don't know how it compares with other cities.

In summary, then, failure and achievements, effort and strife, progress and stability, highlight the pursuit of change process. It could hardly be expected that this Project would be exempt from all these characterizations in attempting to initiate new programs for the retarded.

In the development of programs, the Project recruited many staff members. How they worked, and how their roles fit into the changing scene of retardation services, are the topics to which we now turn.

The Staff of the Project

The professionals' perceptions and feelings about their work and experiences are important for an understanding both of the interplay between Project and Association and of the involvement of the Project-Association combination with the public, the retarded themselves, the parents, and public and private agencies.

Precisely how courses of action are chosen and pursued are always difficult items to explain and understand. The patterns here are manifold and intricate, and we pretend only to highlight themes and events which appear to be dominant or to be directly relevant to critical turning points for the Project itself.

A staff member highlighted one problem, by stating:

One unique theory made it difficult. The person receiving services was the employer of the professionals.

The point mentioned recurred in many events that involved the clash of expectations. One parent, commenting on residential homes, noted that channels of communication were unclear, leading to a short-circuiting at times of authority figures and to over-communication at other times.

The committee every once in a while butts in where they shouldn't and this annoys the staff. The house parents will call people on the committee not the staff people. It takes place because you need a strong executive... Who do the houseparents relate to? People on the committee have tended to be overprotective. They felt the houseparents should get up and get the kids breakfast while the professionals thought all that was needed was that houseparents should make sure the kids eat. Professionals felt if the girls are to be independent, we should let the girls do for themselves. (9/18/68)

Such a clash of expectations between professionals and parents affected the change process. "Laymen", said one professional, felt they could not trust professionals, adding

that "parents have motivations and believe in the professionals' know-how. Professionals may be ignorant and project the image of know-how. There's very little self-appraisal or objective evidence presented by either side."

I felt [he added], that when differences with laymen occurred, this would affect all other relationships with professionals.... People felt their professional roles were not maintained. ...We wanted to maintain professional distances.

...We had no communication with service people; there was no theoretical focus and direction, very little sharing of ideas. There was no feeling of professionalism which I see valued anyway as a facade of pretension and of defense. Even that focus was not there in the clinic. People in the clinic did not know what was going on in the outlying programs and did not appear to be working cohesively with each other in the clinic setting.

I felt there was no leadership, no common focus, people were doing things but did not know what, there was no rationale. We tried to get a more objective focus, but we could not get the service people to accept it.

In general, though, in the whole field of mental health, there's no focus. People don't know what they're doing, laymen and professionals want to maintain their roles and status. Incidentally, both want to help kids. It's thrown into focus when parents and professionals interact.

Such disagreements were worsened by the specific view that professionals were "cold" in demeanor. Various key parents perceived the professionals as "...wanting us to let go. With the right people, we would have been delighted." The reference here, of course, concerns the issue highlighted elsewhere in this Report, of whether associations such as this should demonstrate new programs and then release them into the spheres of operation of other groups in the community, or continue to operate programs for the retarded on the ground that no one else could or would maintain or even initiate such efforts.

Relations between parent expectations and staff capabilities proved tenuous, as here described:

[The Board] had promised the parents they'd keep control, but communication problems were growing. The Board was overpossessive. There were many strangers around, and many agencies, and the Board could no longer keep their finger on everything.

They wanted the Recreation Director to give services to their own children; I wanted to get others to do things and this got to be a budget fight. For example, the Y wanted to run its own programs, and the Board wanted the Recreation Director to have a program for

our own kids. ...There was much ill-feeling about this. The staff got upset and left. The place emptied out.

[Earlier] my understanding was that even if we paid for something, we wouldn't supervise it. We provided the money, got things started, and pulled out and wouldn't supervise, either with an outside agency or with the Parents and Friends.

As this demonstrates, internal differentiation including both the expansion of activities and the addition of staff members with varied responsibilities created stresses and strains felt by many. The addition of many staff members to implement the purposes of the Project contributed to the dissensus that developed. As one professional in an administrative role commented:

The staff were overwhelming many of the parents; the staff was strong willed, and the staff was moving in to wanting a say in decisions and not being subservient to the parents. The parents thought they'd keep control, but communication problems were growing. Many strangers were around; there were many agencies and the Association could no longer keep their finger on everything.

These pressures were experienced by parents, and, as one observed, many professionals

....tell parents how to do things. It is very difficult when you have a mentally retarded child in your home each day, it's difficult to apply their knowledge. We've been disenchanted with many professionals, though we've had some good ones. Most of us feel professionals should live with us for a week and get some real feelings.

"We thought," another continued,

The professionals were cold, they closed down and weren't talking to the parents. There was a wall between us.... The service staff at the Center was ordered not to talk to Board members and the old timers objected.

A former staff member highlighted the clash of parents and staff as follows:

When I came in, there was much bitterness with Parents and Friends. The problem was that the parents organization had so much emotional investment. The Board members were also getting services the agency was giving. Their idea was that the staff couldn't feel things the way the parents did. The volunteers poked their noses in a lot of areas.

One staff member recalled the scene of the conflict as follows:

The whole period was one of ferment. (We) ...didn't want to live it 24 hours a day, and the staff was overwhelming the parents. The staff was strong willed and moving toward wanting a say in decisions, and didn't want to be subservient.

A contributing factor to division between staff and parents was the essentially voluntary character of membership or participation in the Association, and the commitments of time expected from staff by the parents. In the words of one former staff member,

We worked night and day, and sometimes had meetings until one or two o'clock in the morning. Then we had to be at work at eight a.m. It got unbearable at times, but for a lot of people in the Association, this was their life and they enjoyed it. Many of the parents felt they were a beleaguered group and felt they had to shatter the usual standards. The idea was that the usual rules did not apply, for example, state rules on personnel. They talked of the benefits of closeness and warmth, particularly the older parents. The newer parents and the professionals didn't want such closeness. But we were expected to work to all hours.

Thus, the new systems of internal relationships established with the addition of personnel accompanying the Project proved stressful to the prior informal order, and, indeed, dysfunctional for it.

A parent, looking at the impact of the new professionals on the Association in its relations with the community at large, said:

The big mistake was bringing in professionals with the grant and then we tried to do more than we really could. ...The professionals did not have the stature to deal with the city leaders. One group thought we were in heaven; they did not look beyond the next five years. The professionals were strangers in the community. A professional would take months to get known; a parent could call and get services where a stranger might not be able to. (6/10/68)

These consequences of the Project and its new personnel affected adversely the external postures of the Association. As the problems mounted, according to one parent,

The blame had to be put somewhere, I felt we needed a good professional staff but this was against such bucking. Many thought if anything went wrong they could call the president of the Association or Evelyn Kennedy. Many times these were legitimate but many times we had to describe the program of the Project all over again.

The professionals' views are as complicated of course as those of the parents and were similarly affected by the twists and turns of the large number of situations and encounters during the several years of operation of the Project itself. One professional with significant responsibility during the Project commented as follows:

I came to the Kennedy Center knowing what were some of the problems and the numerous turnover of staff, but I felt the previous difficulties were a function of their own personalities and I felt I could do more than people before me and be positive. I may have been a bit grandiose.

...Here were a dedicated and motivated ...group of parents but they were unwilling to yield authority and to allow us to play professional roles. They tended to be intrusive and if the decision involved their own child, they wanted to sit in on the conferences.... They did not really understand how the organization that provides clinical services functioned. (6/13/68)

Derivative from this point was the comment of one professional that "the professionals wanted to be known as employees of the Kennedy Center not of the Parents and Friends Association." (10/4/68)

A parent sensitive to both parents and professionals, summarized the clash of these perspectives as follows:

The parents had run things on their own, and they were afraid they could not be able to run things and the professionals would come in. Many parents couldn't come to workshop meetings and they were interested in it only for their own. When the professionals came in, they objected to the salaries. How come you're paying that much? At one meeting, they asked how much are you paying this one or that one.

Maybe we grew too much too fast. With the grant, we needed professionals and this required higher pay, and an increased salary budget. It got scary. The last budget was \$400,000.

A clinically oriented professional observed that we

...wanted to turn into a therapeutic clinic.... I was appalled by the previous clinical services, with poorly trained personnel, and a low level of workups. The recommendations were stereotyped. ...[The Director] felt we could perform many things in line with becoming a model center for the whole country. He used the idea of a community-based spectrum of care.

...We launched a group parent counseling program, but ... few of them came and the bulk never did. The main point was a tremendous denial that pervaded their thinking of their own emotional involvement. They re-directed their involvement to the operations of the Center.

There was an immense amount of hostility to professionals; the parents felt the professionals had not solved their problems as parents. The professionals still can not undo retardation.

While this was going on, we got a good staff together and began to develop meaningful relationships with the school systems, where they came in for conferences. I began to notice pressures on me. ...I soon discovered communications were blocked at the Center. ...I noticed inconsistencies among the professionals, parents and the state. I opted strongly for joint meetings to discuss problems with them.... All along there was constant talk about new programs, but there was little respect for the people who ran the programs. [Administrators]...were totally unsympathetic to professional staff needs, and tried to interfere with our handling of cases."

In sum, expectations by both professionals and by parents proved to be incompatible with each other. Little lasting congruence of perspectives occurred, and this directly led to staff turnover and to parent dissatisfaction with programs. The critical end result was a decrease in morale within the Project and within the Association. Parent dissension about the Project and the affairs of the Association itself succeeded the pride expressed over the many accomplishments which their efforts had yielded and the satisfaction they felt when the grant to initiate the Project was awarded. The Kennedy Center building which embodied the fruits of the parents' lengthy and serious efforts now housed the state-operated Regional Center for the retarded. Various programs -- the workshop, Tri-Us, recreational programs, the residences, -- remained with the Association, as did clinical services for a time, but very many efforts had moved out of their hands and into the orbit of the state's Regional Center. A mixture of pleasure and dissatisfaction remained, as well as some puzzlement about why the good intentions and serious effort had yielded fewer benefits for the retarded than were contemplated at the beginning and in the early phases of the pursuit of change.

CHAPTER IX

THE PARENTS ASSOCIATION AS DEMONSTRATOR OR OPERATOR

Students of organization life and activity have not studied sufficiently the unique contribution of the parent self-help group as reflected in the tremendous growth and development of this phenomenon since 1949-1950, the years of its beginnings. This organizational model does not exhibit the characteristics of the typical American voluntary social welfare organization.

In 1949-1950, in a number of urban centers, including New York City and Minneapolis, parents gathered together to start what has become the parent group in mental retardation. Similar developments were reported in Western Europe.

Parents had seen what retarded young adults and adults had accomplished in the recent war effort. They had observed the impact of rehabilitation services made available to veterans by a grateful nation. They had been witness to the growth and changes in their own retarded children when exposed to educational and other programs.

Parents, too, had found the helping professions convinced that institutional placement of the retarded was the only humane solution. Strangely enough, most of these professionals had never worked with the retarded. They reflected the stereotypes acquired in graduate education and reinforced in professional practice. They perceived retardation as a clinical entity, associated with organic defect, and incapable of any modification through planned intervention of any kind.

The urgency, the need, the precious little hope that parents had, spurred on developments which created a movement: a parents' movement.

What have been some of the characteristics of this movement?

The basic helping ingredient that persist to this day are the mutual psychological support that parents give to each other and the beliefs that they are not alone, that mental retardation has happened to others and that together the individual parents can do something about it. Together they form a bulwark against the rigidities of the voluntary and public health, education, and welfare agencies and the lack of understanding and support of the helping professions. They defend themselves against a hostile environment, in the same way that members of minority groups develop coping mechanisms. This feeling of alienation, a great deal of it real, but some not, makes cohesiveness possible.

Their "shared fate" as parents of the mentally retarded can be mediated by talking about it to people who understood and who do not make them defensive and uncomfortable. The daily problems of living with a retarded family member can be dealt with by learning from others who share the same fate and who also share their successes, their failures,

their beliefs and in many instances their resources, such as homes and offices. What is expected from the professionals comes through more easily, more quickly and more meaningfully from another parent.

The emphasis in the beginning was on service to the retardate, rather than to the total family or to the community. This child-centered emphasis was dominant for a long time and is slowly yielding to change as the impact and availability of other services make themselves felt. The feeling that a concrete service to the retardate would lessen the stress and strain of other problems in family and community living was viable, in that the retardate had so few services compared to other family members. It was often felt that intra-family problems, for example, would lessen if the retardate could attend a daytime group activity, where he or she could learn social skills and become more independent. Parents also perceived in their own suffering and upset (as well as that of the normal siblings) a relatively minor problem that should not detract or take away from the priority of service mandated for the retardate.

In all of these developments, parents were attempting to innovate a role. They had a reference group, which they developed themselves, a group that was helpful in many ways. The general society, however, did not help in the shaping of a role for the parent of a handicapped person. A person who had among his deficits intellectual limitations was the object of negative communal value judgments. The role in which society cast the retarded individual became the target for the parents' movement.

In the beginning, parents started with their own resources: their interest, their motivation, their money and facilities. They used their basements, living rooms, backyards, offices and any other space to start small groups for some educational stimulation, for day care, for recreation, for socialization, for parent relief. Parents manned the services with the aid of normal siblings, interested and concerned neighbors, relatives and friends.

Their input was productive, in that little and large gains by the retarded, who were given organized services for the first time, made possible the second step: bringing in professionals who could help develop a small class, a workshop, or a recreation group. Parents turned their efforts to raising funds, gaining friends and supporters, and extending the array of programs to meet varying needs at different levels of functioning. Their efforts yielded a harvest of results; they began to build viable agency structures with growing community support from the legitimated community funding groups, and they began to turn over some of the functions to professionals who were interested and whom they could entrust with such responsibility.

Nowhere in the parent self-help group has complete professionalization taken place. A number of reasons account for this. Parents perceive this organization as their group and, as a consequence, wish to keep parents an integral part of the structure. They have seen the consequences of full professionalization in other agencies, where they attempted to receive service and felt a lack of human warmth and understanding. Finally, parents do not fully trust the professional community, where they still see too much evidence of ineptness and lack of interest regarding the mentally retarded.

As the organizations grow, the Executive Director tends to change from an unpaid to a paid parent. Later on, a non-parent becomes the Executive Director, a board structure develops and a hierarchy of positions, -- both volunteer and professional, -- follows.

As a group of people with middle class identifications, actual or aspired, this group becomes articulate about major lacks in the community that have meaning and relevance to them. Consequently, because of their situation, their upwardly mobile aspirations, and their value system, the parents want education and jobs for their retarded children. These feelings, desires and interests form the backbone of a series of agency or unit strategies. Thus, parents group together on a state basis and go to legislatures to seek what is already available for other children, and to remove discrepancies in opportunities for children who are normal and for those who are handicapped.

They secure mandatory legislation for classes for educable and later for the trainable children. The units or association have initial strength in the urban areas. They help rural groups to see the validity of their position and win support from rural legislators. They seek out ways to create, with public funds, vocational rehabilitation programs that include workshops for their retarded young people, so that they can earn money at jobs which restore dignity and morale. The parents help federal dollars flow into state vocational rehabilitation programs which concern themselves with the retarded.

In this process of becoming strong advocates for the retarded in the state legislative arena, parents alienate and feel alienated from many professionals involved in such services. These professionals are accused of lack of interest, or lack of imagination, in developing programs for the retarded, or lack of responsibility in carrying out what they are authorized to do. Perhaps such estrangement was inevitable as parents became parts of political alliances with other non-professional groups and thus do not become dependent on professionals to achieve their goals.¹

In 1950, a National Association for Retarded Children (NARC) was formed to consolidate the gains of the isolated local and state units, to accomplish nationally what was needed to bring the retarded individual into the mainstream, and to insure his basic rights. This association now has about 200,000 members and about 1500 local units. Its power is in the hands of a board of directors dominated by parents.

Three major policies developed by this group are of relevance here:

1. The NARC authorized units to bring "non-parents" onto their boards in numbers up to 25%. This move acknowledged the need to spread out and involve the community to a greater extent.

¹ In many ways, there is a parallel between the recent programs of the U.S. Office of Economic Opportunity and the Parent movement in that the establishment had to yield to new forms, and new delivery systems were developed to serve a group that hitherto nobody wanted to help.

2. At the same time, the national organization adopted a policy of non-discrimination and urged state groups to do likewise. Local units were asked to drop separate but equal facilities and programs. This policy also meant that local units would bring in minority members, as well as the poor, into their membership. The impact of this policy has been rather limited; it has not been fully implemented, and no unit has been dropped for discriminatory practices.
3. A policy of "secure, not provide" services was adopted and was seen as the beginning of an all-out effort to use community resources and to place the responsibility for services where it correctly belonged in the other agencies. This policy too has not been fully implemented. Many units are ambivalent; if they do not offer direct services, they fear that they may lose their membership base.

The "Kennedy thrust" in 1962 was a major turning point in bringing more services to the retarded, in changing attitudes, and in further bringing retardation out of the shadows. However, it is questionable whether the Kennedy efforts would have been successful if the groundwork had not been laid in thirteen years of struggle by parents and others interested in the retarded.

The existence of this parent movement testifies to contradiction in our social system. It reflects a situation where parents of the individuals affected take responsibility for changes in the social system. Overall, this parent self-help group, as exemplified in the Parents and Friends, perceives the parents as the key change agents in the community as it seeks to improve, extend and strengthen services. Non-parents are seen as outsiders to the efforts undertaken and are viewed with ambivalence as objects for change or as potential helpers in the process.

As parent associations for the help of retarded children developed, few if any members questioned the belief that there were benefits to be gained from the interaction among people with similar problems. There was little or no disagreement with the stated aims and purposes of the National Association for Help of Retarded Children as stated at the time of the formation of this group in 1950. The aims and purposes were:

1. To promote the general welfare of retarded children at home, in institutions, and in all types of schools.
2. To further research in all aspects of mental retardation.
3. To develop a better understanding of the problem by the general public and to cooperate with various public and private agencies.
4. To further the training of personnel in the field of mental re-

tardation.

5. To encourage the formation of parents groups and to advise and assist in the solution of common problems.
6. To implement and promote legislation.
7. To serve as a clearing house of information regarding program development.

During the past seventeen years, many conflicts in philosophy and purpose have developed within local units. When few programs or services were available for the mentally retarded, it became the clear cut purpose of many local parent groups to undertake the development of various programs to meet the needs of their membership. The services which were developed were those required by the mentally retarded if any or all were to have an opportunity to reach their potential.

This is a major difference in community planning for the non-handicapped as compared to the handicapped. The main objective for the non-handicapped to provide service, often before it is requested, for fear that its absence may have an irreparable effect on the individual, showing itself sometime in the future as a handicap.

For the already handicapped, there is little or no concern about contributing to the existing deficit and much concern about providing programs or services to permit the individual to function at maximum. It is ironic that these two views and practices are so common today when there exists widespread acceptance of the theory that each community has the responsibility for the provision of services designed to meet the totality of needs of all who may require them.

To secure, then, for the handicapped what is accepted as their common right, a parents association must first identify needs, and then plan and conduct programs and provide other services to demonstrate not only what is needed, but what can be accomplished.

Conflicts in philosophy and purpose arise during these activities, between two groups: Those who want their association to demonstrate the value of programs and then turn them over to other community agencies; and those who want to continue to operate the programs that they have begun.

The experience of many parent groups has shown them that the fastest way to get appropriate agencies to accept responsibilities for specific services is often for the local association for retarded children to operate them on a pilot basis. Some local association will view their role as that of a very long-range demonstration project covering a period of many years during which it may serve as a temporary pilot agency for dozens of different programs.

There is common agreement that parent associations should be involved in creating and supporting projects for all of the retarded, for influencing other agencies, both public and private, to understand and accept their responsibilities for providing services, for participat-

ing in public education programs to inform and to disseminate information relative to needs and programs.

The major disagreement centers on the belief that many parent associations are reluctant to ultimately yield both control and responsibility for parent sponsored programs when others, equally or better able and willing to assume sponsorship, are available.

Those who advocate the withdrawal from, and turnover of, parent sponsored programs and services to other agencies, feel that the major part of the primary object has been achieved once a program or service is developed and demonstrated. They contend that this should be a satisfactory achievement for the parents' association, which can then direct its attention and efforts toward attaining the same end with any of the numerous still unmet needs of the mentally retarded.

The reason for this course of action is the belief that parents' associations have more freedom and flexibility in developing programs than do most governmental agencies. They can provide a greater range for experimentation in program and service development, as well as opportunities to deviate from what may no longer seem appropriate.

Governmental agencies, dependent on the public for finances and authority, are too often seen as bound by a traditional, conservative approach to social problems. Those who follow this approach believe, then that the parent associations should be demonstrators, and demonstrate just long enough to show that it can be effectively done. Once demonstrated, they should not be the operator but should turn to another area to make maximum use of this unique license of freedom and flexibility in showing others the way.

In the final analysis, all parent associations set out to be demonstrators. The more effective ones relinquish responsibility at a point where continuation would cause them to become operators. The less effective associations are those who do not yield and, as a result, lose their unique individuality and potential for leadership. Others are better qualified to carry on what the associations have pioneered. Restricting or delaying other experimental programs and services may be the end result of protracted operation after a pioneering demonstration has led the way.

The Organizational Environment of Parents and Friends

The most relevant environment for people is people. People interact with other people -- their most meaningful environment is a social one. In similar fashion, the most relevant interaction environment for organizations is other organizations. Large-scale resources -- financial, spatial, manpower, technological -- are seldom available except from organizations and to organizations. Even where private individuals possess large amounts of scarce resources they are almost always administered as trusts, foundations, or corporations. Seldom are large-scale resources ever available to individuals. They are distributed only to other organizations. Thus, action programs such as the Parents and Friends of the Mentally Retarded of Bridgeport, face two requirements: (1) it must interact with other organizations in order to gain and manipulate resources, and (2) they must themselves operate as an or-

ganization in order legitimately to claim such resources. These two requirements have important implications for the Parents and Friends.

As has been suggested earlier, the Parents and Friends group is made up largely of action-oriented citizens. As members of the local business, professional, and industrial community, members of the organization are committed to a set of values which emphasize privately-initiated action, personal responsibility, local control, and fiscal integrity. This orientation toward what is essentially a "business" type of operation was brought to the Parents and Friends by the active members.

Moreover, the Parents and Friends group has enjoyed substantial relations with the local business community. The industries of Bridgeport are a primary source of fund-raising of local patronage, of manpower, and space. Interaction between these business organizations and the Parents and Friends group implied the assent and admiration of the business community for self-initiated action and for the vigorous efforts of the group to find their own private, collective solutions to their problems. To maintain this kind of support from the business community, the organization had to continue to exemplify these values in securing and providing services for the mentally retarded.

Another category of organizations which comprises a relevant environment for the Parents and Friends is the public and private social welfare and social service organizations of Bridgeport. These include the schools, the health agencies, the Family Services, and the specialized social agencies of the community. It is with these organizations that the Parents and Friends must coordinate and construct its own programs. In addition, contacts with these organizations are made through community fund-raising agencies and coordinating councils.

The orientation of these organizations is markedly different from that of the business community. They are service-oriented. This is a professional social welfare ethic, more concerned with the quantity and quality of client service and the assurance that such service will continue than with questions of ownership or private vs. public action.

The people who staff these agencies are largely professionals in the social welfare fields. Their concerns center on providing expertise and guarding professional autonomy. These are issues which are not stressed within the value framework of the Protestant ethic. In addition, they are constantly concerned with problems of fund raising and the allocation of finances. These problems most frequently represent the crisis areas of private agencies and the greatest threat of interrupting services. Such problems are not as critical in public agencies.

What exists is a dualism in the organizational environment of the Parents and Friends: personal individualism on the one hand and a service-oriented professionalism on the other. These are, to some extent, mutually exclusive sets of values.

Nowhere is this dualism better reflected than in the relationship between the Parents and Friends and the State of Connecticut. On the one hand, the Parents and Friends have been a vigorous private voice urging, encouraging, chiding and occasionally applauding the state government with regard to its programs and policies for the retarded. They have

been an effective voice in the halls of the State Capitol and have done much to secure services for the retarded. In this respect, they have operated much as other lobbies do -- protecting their interest and seeking further services for their clientele. In this fashion they have sought services in the public sector which would add to and expand, but in no way threaten, their interests in the private sector.

On the other hand, this same group, after erecting an edifice to provide services to its clients, found it necessary to turn to the state to assume the responsibilities of running the center for its clients. The conflicts and ambivalence involved in turning this cherished facility over to the state are an accurate representation of the desire of the Parents and Friends at once to retain its autonomy and alternatively to provide high quality professional services to its clientele.

The resources required to provide services desired, expected, and in time indeed demanded, became extremely burdensome. As a consequence, a crisis of values occurred that in capsule, over simplification form can be stated as services versus autonomy. At one point, where this issue was critically joined, autonomy yielded. The state "took over" the building.

While this mixture of organizational perspectives was problematic in approaching state government, it was not problematic in the case of the federal government. The relations between the Parents and Friends and the federal government have been conducted in a fashion similar to other contracting arrangements. The grant application stipulated a series of services to be performed by the Parents and Friends and included a budget for the provision of these services. The form of the grant allowed autonomy on the part of the organization, placed responsibility for action upon them, and required a "product". Thus, the federal grant posed far fewer value conflicts than were posed by relations with the state.

In short, the Parents and Friends of the Mentally Retarded of Bridgeport has not existed in a social vacuum, untouched by the community or other agencies with which it has had to act. Its statuses as a supplicant to the business and industrial community and also to the state and the federal government has left an indelible impression upon it. And to a large extent its internal organizational policies, its problems, and its achievements have been determined by the nature of the environment with which it has had to deal.

CHAPTER X

ISSUES IN THE PURSUIT OF CHANGE

One of the most fundamental issues in a consideration of the results of the "Project to Demonstrate Community Based Services for the Retarded" is that this effort represents a prototype of a new model of social action organization. The model of social welfare organizations has been that of a community agency, a church agency, or a professional agency serving a naive clientele who delegate the functions of expertise to the agency and submit to intervention in their personal problems. Not only is this the model for social welfare organizations, it is the very model for the "practice of the profession of -----." The archetype of the professional practitioner suggests the pervasiveness of the ideal of professional autonomy, expertise, and control in the solution of the client's problem.

An alteration is occurring, however, in the organization of many social welfare services as egalitarian ideologies come to be imposed upon both the political and social institutions of our society. The initiation of the "Poverty Program", the "Great Society", and numerous other social action programs has been marked by a commitment to the participation of clients in the control of social welfare services. This remarkable innovation suggests, for the first time, the right of the client to examine the policies and programs of the social welfare agency before they are begun. It recommends to the professional a sharing of authority with his client. It recognizes the limitations of professional expertise and, by extension, of professional control.

This is a revolution in the provision of welfare services. But as with all revolutions, it has been set out by a social tide on an unmapped shore. We simply do not know what the results will be. May we foresee the growth of enthusiastic participation of the client in his own behalf where this has been lacking before? Do we face the corruption of knowledge and expertise? In short, is it possible to democratize the provision of welfare services without ultimately destroying the quality of programs?

There are, of course, no simple answers. What we must do is to examine closely those programs in which such changes have occurred. This is precisely what we will attempt in the following pages, for in the case of the Project we have an instance of client control over the administration of services.

Peter Blau and Richard Scott have discussed the implications of "who benefits" from the organization of services. They point out that there are four publics with whom an organization is likely to deal: (1) the owners or operators of the organization, (2) the members of the organization, (3) the public-in-contact -- a specific public which the organization serves, and (4) the public at large.¹

¹ Peter M. Blau and W. Richard Scott, Formal Organizations: A Comparative Approach (San Francisco: Chandler, 1962,) pp. 42-45.

Organizations are most often established with service to one of these publics as a foremost goal. Blau and Scott note that the serving of different kinds of publics has definite implications for the internal structure and operation of the organization, that as the relevant public shifts, so do the processes within the organization and the relationships of the organization with those outside of it. We may examine in this light the "old" format for providing welfare services and the "new" format -- professional control and client control. While our remarks undoubtedly have relevance for other kinds of services, we will direct our attention specifically to the providing of services for the mentally retarded.

The most obvious locus of services to the retarded, according to the "old" format, is the state agency. The state agency serves a hierarchy of publics: first it must serve the community, since it is an agent of the community. Second, it serves the parents of the retarded and the retarded themselves, its public-in-contact. Third, it serves its staff. And last, it serves the state bureaucracy of which it is a part.

The state agency which takes responsibility for the retarded is, then, a multi-functional agency. One obligation is to protect the community from the retardate, viewed here as one who is unfamiliar with the norms of the community and whose behavior is not governed by the same codes of conduct which apply to more thoroughly socialized individuals. This problem becomes especially acute in the case of the emotionally disturbed retardate or the retardate who responds to the frustration of low levels of achievement. The community views the retardate as "different", "unusual", "exceptional", and fears him. Thus, one of the state's obligations is to furnish "protection" to the community from this potential "deviant".

A second function of the state agency is the protection of the retardate from a potentially hostile or manipulative community. In this capacity, the state operates as the agent of the retardate in insuring him a safe existence. As an extension of this function, the state provides care and sustenance for the retardate whenever he is left without a supportive family environment. The state is in a position to provide the retardate with the necessities to sustain life when these are otherwise unavailable to him. In this capacity, the state accepts the retardate as its dependent.

In terms of social welfare service, the state also provides "treatment" and "education" to the retardate. Inasmuch as retardation is defined as a medical problem, the state provides medical facilities. Insofar as it is an educational problem, the state provides special training. The essential point remains, however, that the state acts both as an agent of the community, and as an agent of the retardate and his family.

In addition to these interests, the state is also responsible for a vast array of physical facilities and a large number of people who staff these facilities. In support of these individuals and facilities it submits complex budget requests to the legislature and thereby makes its claims upon the taxpayer's dollars. Thus, it must submit to two ultimate authorities -- the community as represented in the legislature, and its staff which is represented in its internal functioning.

These varied and oft-conflicting interests get played out in legislative and administrative processes to which few are privy. And most important, the client group -- the retardate and his family -- are only a single voice in these processes, and not necessarily the

loudest of the voices heard. Nevertheless, this is the format under which social welfare services have traditionally been provided in our society. Under this format the client has no control of the resources necessary to the solution of his problem. He requests -- not implements. He is granted no authority.

The recent reaction to the provision of social welfare service in this format has been articulate and convincing. It is argued that the establishment of bureaucratic expertise dehumanizes the client; that centralization of authority and decision-making, it is argued, removes the formulation of policy from those who are closest to the problem, that depersonalization of the client deprives the professional of his most valuable source of information concerning the client's problem. The suggested solution is nothing short of a total reorganization of client-agency-professional relations. And this has been the course of events.

The Parents and Friends of the Mentally Retarded of Bridgeport represent an organized client population, founded by a public-in-contact which perceived that needs were not being served by the state. In response to the limited services being offered by the state and the extensive services perceived as necessary by the client population, the Parents and Friends Association was formed. The critical difference between the state and the Association as providers of services is that in the latter case the membership transformed itself from being a public-in-contact to a managing public.

This shift in structure had wide ranging implications for the kinds of services which would be offered by an organization geared to the retarded. It had further implications for client-professional relations, in terms of control, perceptions of expertise, and professional autonomy. Finally, it had implications for the degree of flexibility available for innovation and change in dealing with the retarded. Such a shift amounted to a bureaucratic revolution in which the lines of authority, communication, decision-making, and expertise had to be re-adjusted.

An organization directed by the parents of retarded children or by other people totally oriented to the situation of the retarded must be qualitatively different from a state department which is assigned responsibility by the community and which is responsible for facilities and staff. The Association in marked contrast to a state agency, has one interest primarily in mind -- the retardate and his parents, as exemplified by the membership of the organization. The Parents and Friends is organized with manifest devotion to the interests of this group. For this reason it is highly responsive to those people who have the most intense interest in the problems of retardation. It does not suffer an obligation to community attitudes or prejudices, or to the community as a fiscal agent. Nor does it suffer an obligation to a highly organized and vocal staff. Its commitment is not administrative or intellectual. It is founded in the depths and agonies of parental concern. For these reasons, its strengths and weaknesses differ substantially from those of a public facility.

A voluntary agency for the retarded could not be expected to orient itself to the traditional functions and interests of a state agency for the retarded. It could not, for example, respond to the definition of the retardate as a potential deviant from the community. The dominant danger to the retardate and to his family would be perceived by such a group as coming from a hostile community that imposes stigma on retardation or as emanating from the impersonality and arbitrariness of a state institution. This view of the state school as a hostile en-

environment would be particularly painful to a parents' group as it became obvious to them that each retarded child was likely to spend some portion of his life without the comfort and support of his family. These parents would not wish to see their children dependent upon the state or forced into isolation from satisfying social relationships by the force of prejudice. Finally, a parents' group would be very likely to question the "treatment" or "education" which was provided the retardate at a state school.

It is clear, then, that the impetus for the formation of a parents' Association arose from a unitary, focused interest group seeking the provision of services which they found unavailable from a state agency. As a result, they established a bureaucracy of their own design, one which operated under their guidance and control. This new bureaucracy was oriented towards service and committed to directly satisfying client needs. The goal structure shifted from isolation from the community to integration in it. To this end, the "Project to Demonstrate Community-Based Services for the Retarded" was initiated to obtain services and to integrate the retarded with the community.

The first problem which the Project faced was the lack of clear demarcation between the purposes of the Project and those of the Association. With a confusion of purposes, there could be little possibility of escaping confusion of resources, because use of resources is contingent on commitments to defined goals. Overall, the Association and the Project had different obligations and different commitments.

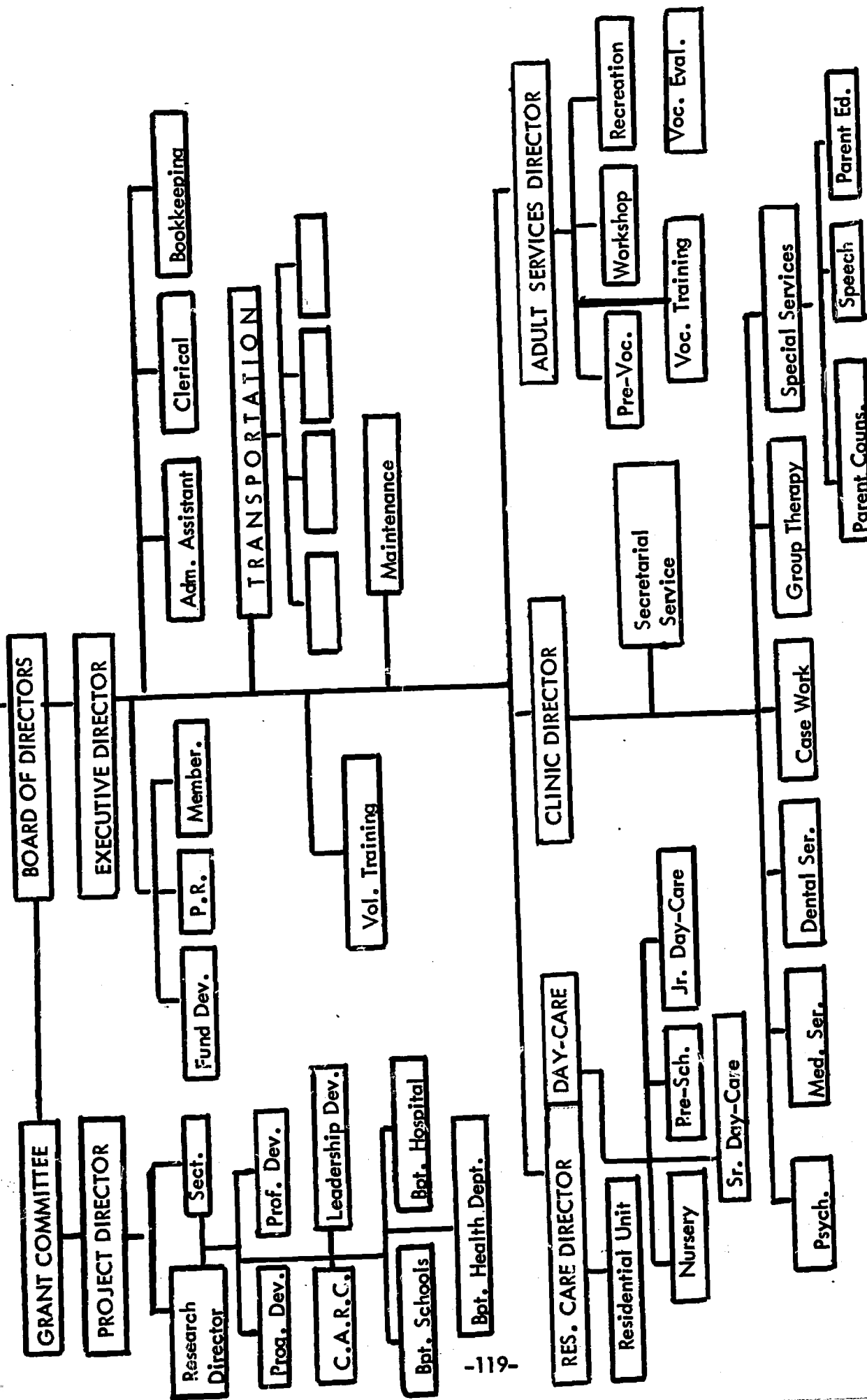
With the stage set for conflict over the purposes and resources of the Project -- and with the differences in obligations and commitments, there was little possibility of avoiding severe fractures in the lines of authority and responsibility in this fragile structure. The organization now consisted of four separate bodies and three executives. There was a Project Director, an Executive Director of the Kennedy Center, and a President of the Board. There was a Project staff, a Kennedy Center Staff, a Board of Directors, and the membership of the Parents and Friends who ostensibly represent the parents of retarded children in the Bridgeport area and who, in turn, are ostensibly represented by the Board of Directors.

That the resulting lines of authority, responsibility, decision-making, and communication are vague, ill-defined, circuitous, and complex is amply demonstrated by the Staff Function Chart which was published by the Center on December 17, 1963. Chart 1. Statements of the chart are clear and direct: the relationship of the Project Director to his staff, the relation of the Executive Director to his staff, for example. What is unclear is the relationship of the Board of Directors to the Project staff, and the relationship between the Project Director and the Executive Director. These very confused and intricate relationships form the shifting stage on which the drama of the Project was to be played out.

Personnel and the Project

A critical area of development of the Project was, necessarily, the accommodations which would have to be made between providing appropriate services to the client group and the maintenance of a code of professional behavior. As has been described above, it was highly probable, from the structure of the organization and the character of its goals, that conflicts would arise. As long as the definitions of the legitimate goals of the organization and the place of the Project within this set of goals were allowed to vary, there could not be clear lines of authority and responsibility. As long as the Project staff, the

PARENTS AND FRIENDS OF MENTALLY RETARDED CHILDREN, INC.



- | | | | |
|----------|-------------------|----------|---|
| Level 1) | Executive | Level 3) | Professional - Supervisory |
| Level 2) | Program Directors | Level 4) | Professional |
| --- | --- | Level 5) | Program specialists |
| --- | --- | Level 6) | Clerical, Maintenance, Program Assistants |

staff of the Kennedy Center, the Board of Directors, and the Parents and Friends had different ideas of the role of the Project within the overall organization, there had to be conflict.

Conflict within organizations, however, is not a single social process which breaks out without apparent cause. It is usually not a product of individual personalities. Rather it is most often a product of social structures which obstruct the resolution of problems, and of long-standing disagreements and misperceptions. Before there can be conflict, there must be interaction. Thus, we may expect that the first phase of operation of the Project must have been marked by interaction between all factions and segments of the organization in an attempt to conduct the business of the Kennedy Center and the Project as well. The organization of this interaction, however, was not clear to the participants and, as a result, disagreements occurred. When these disagreements became prominent enough in the interaction of the members of the organization, attempts at accommodation were initiated. These included (1) ad hoc solutions to specific problems, (2) changes in personnel, or (3) changes in organizational structure.

The first form of accommodation is generally a short-lived solution. New problems arise and must be solved, and the business of the organization can become mired in a constant series of crises. The second form of accommodation is also generally short-lived, for an alteration in personnel cannot resolve the problems of variant definitions of the situation, inadequate processes of communication, or vague structuring of authority and responsibility. It is only the third accommodation which allows for long-range solutions to conflict situations.

Exactly how this process in the resolution of the conflicts engendered by the confused structure of the Kennedy Center and Project occurred is unclear. After an initial period of interaction and organizational operation, the conflicts between the Project's professionals and the Center's Board reached a point where no further accommodation could be made between the parties to the conflict. The Project Director and the Board had a serious disagreement which resulted in a series of resignations and the instability of the entire organization. This complex occurrence is described in the yearly Progress Report submitted in July 1966 by the new Project Director, Stanley Meyers. (See Appendix V).

This report gives an accurate account of the sequence of program development through discussion, planning, initiation, and full scale implementation. He also describes the resultant conflicts between the Project Director, the Executive Director, and the Board, with the involvement of both "old" and "new" parents from the constituent group. This series of conflicts resulted in the resignation of the original Project Director, Maurice Mezoff, plus many staff members, and his eventual replacement with Stanley Meyers.

What is most interesting is the nature of the alterations which were required to establish an effectively functioning Project Director and Executive Director and to bring the Project more closely in fact in line with the thinking of Board members. Both these offices were filled by the same person, Stanley Meyers. In this way, the Project and the Center received the maximum amount of coordination, and the power of both these offices was integrated. In terms of the techniques of administration, this was an effective move. There was now a substantial power base from which the Director could operate. He had a maximum of resources and a maximum control of these resources in meeting specific goals. The net effect was to decrease the apparent split between Project and Association, at least in

the view of Board members .

"The Board's reluctance to delegate authority to professionals was the undoing of the Project," according to one observer who felt this led to the traumatic split between the first Project Director and the Association. He added that throughout the episodes of strife and turnover the Board members perceived the Project as merely an adjunct to the Association. The distinction between Project and Association was "artificial"; "there was no distinction," he concluded. Thus, the combining of the Project Directorship and the position of Executive Director of the Association in the person of Meyers (1) merely continued the previous pattern pursued in practice through a close working relationship of Project Director and the Association Executive Director, and (2) served to maintain, indeed to strengthen, the inferior position of the Project to the Association's Board.

The problem, however, was that the integration of these two roles assumed the convergence of ultimate goals. Placing one person in both these positions implied that the same person could direct what were anticipated originally as two quite distinct organizations. Furthermore, the assumption was implicit that these two organizations had similar goals and as we have stated above, this was not the case.

The Kennedy Center was an agent of the Parents and Friends of the Mentally Retarded of Bridgeport, a special interest group seeking to maximize certain returns in the form of welfare services from the larger community. The Project was an agency established to serve the greater community through the initiation and integration of programs and the provision of new services to current clients where these were otherwise unavailable. These sets of goals were in theory incompatible. The inevitable utilization of the Project's resources for the Center's programs resulted from the fact that the Association itself remained as a consistent locus of power during this period. The appointment of a single individual to the Directorship of both organizations was an administrative accommodation to the conflict. But it made the goals of the Project permanently subordinate to the goals of the Kennedy Center and the Parents and Friends Association.

That this accommodation was successful in terms of the everyday functioning of the organization is made clear in Meyers' Progress Report of July 1967. Indeed it would appear that the conflicts between executive personnel and the Board had vanished. What is not spelled out is the implication of this structural accommodation for the goals of the organization and for those of the Project (seeking to broaden the involvement of a host of community agencies with the life and welfare of all the retarded in the Bridgeport region).

There are two related problems, then: the structure of the organization and the differences in commitment. As we have suggested, the organization was constructed in such a manner that there was likely to be confusion between the Board and the Project Director. In addition to this potential for confusion, there was a differentiation between the Board of the Association and the professional staff, which was even more destructive of the required processes of communication and trust. This was the issue of "being a 'parent'".

One who does not have a retarded child must go far and perform well to be accorded full trust and confidence by those who do. Everyone who does not have a mentally retarded child must prove himself unselfishly and totally devoted to these children before he can be

fully accepted by their parents.

The result of the importance of "commitment" to the Parents and Friends Association was a mistrust of all disinterested parties until their loyalty was unequivocally proven. In their scheme of values, the untrained lay person who shares a commitment to the children is to be preferred to a fully trained professional who has not demonstrated this commitment.

This willingness to use untrained but committed persons is illustrated by the response given to an Agency Self-Study Questionnaire which was distributed to all social welfare agencies in the Bridgeport area. In response to the questions "Social welfare manpower is a long range problem for the total community. What plan would you suggest for solving it?" The Association answered as follows:

More intelligent use of volunteers. Report to untrained personnel or, more accurately, personnel who would not fit into the general definition of "professional" but who by temperament and experience could provide valuable service. Through use of sub-professionals or in-service training. Also, by encouraging universities to offer training courses on a sub-professional level where feasible.

A second issue which prompted confusion and difficulty was the lack of definition of lines of authority and communication in the organization. Especially prominent here is the role of the Board and its relations with the professionals of the organization. Because of the imprecise relations between various levels of organizational structure and because of the fact that the Board considered themselves to be above reproach by dint of their "commitment" -- a commitment which the staff had to demonstrate continuously in order to enjoy the confidence of the Board -- the staff was under constant criticism. The resulting relations between the Board and the professionals are characterized in the response of the agency to the survey mentioned above. To the question: "If your agency's operations have been handicapped in recent years by staff turnover, what steps do you think can be taken to correct the situation?" The Association's response follows:

Our operations have been handicapped by staff turnover. We feel that some of this turnover was due to an "employees market" in that there are many more job openings than there are trained personnel to fill them. Some may have been due to a lack of clear-cut delineation of authority of director and board members. Some turnover is also due to the changing nature of our programs.

A basic aim of the Parents and Friends of Bridgeport in developing the plan for the Project was to enhance the existing environment, both cultural and structural, in the community, insofar as that environment was thought not to provide adequate facilities and services for the mentally retarded and their families. This enhancing aim for their efforts was accompanied by another aim, that of creating a new environment. Creating an environment implied in the thinking of the Parents and Friends sponsors, that the existing environment in Bridgeport for the mentally retarded and their families was inadequate, impoverished, or indeed absent, and that the potential environment for the retarded was substantial but in need of development.

The sponsors of the Project saw themselves then as agents of change and of a peaceful but resolute effort at what might be considered a revolution. The environment had both to be stimulated and reorganized. Old systems had to be invigorated, to acquire new interest in the retarded. Their existing efforts were viewed as lagging and in need of stimulation on the basis of changing expectations. The Parents and Friends felt that existing agencies, public and private, provided only very limited and inadequate help for the mentally retarded and their families.

As leaders in social change, the Parents and Friends defined themselves as a catalytic organization and as peaceful revolutionaries. The mechanism of change selected was to establish a special Project supported by funds obtained outside the community. The Project would supply financial professional resources that would help bring about the social changes within the community that they so ardently desired. These new resources made it possible to employ professionals who could participate, direct, and work jointly as implementers with the sponsoring group in providing the stimulus felt to be essential for social change.

The appraisal of the community and the agency's relations to it must include an appreciation of how a private association of volunteers and interested citizens can deal with and interact with existing public and private agencies. Methods of access and the mechanisms of change are both chosen and forced upon a private organization of volunteers when it confronts existing organizations whose efforts are deemed insufficient and inadequate, whose range is considered too limited.

The device used for change was a Project sponsored by the organization, a Project to be staffed by personnel recruited by the organization. This entailed the development of an internal structure that was new, one created by an organization the members of which felt additional resources would help them accomplish their purposes. Was this new structure effective in producing the changes desired?

One may also ask how the new structure that was created interacted with the existing structure of sponsors, how its aims and efforts coordinated with the aims and efforts of the sponsoring agency. Professionals and others were recruited to the Project fundamentally as implementers of the sponsors' beliefs that change was essential and could be brought about by adding specialists.

Was Bridgeport a model for regional centers for the retarded, to be duplicated elsewhere but under state funds? The Regional Center concept implied clearly that the state should establish organizations to provide service programs in areas where such programs did not already exist either under public or private sponsorship.

The Parents and Friends of the Mentally Retarded of Bridgeport, Inc., planned a physical plant for a program of varied services, built the facility, established a program of services, and used this operating facility as an example of what could be accomplished in the development and operation of comprehensive programming.

It appears that the physical plant and the organization of services associated with the Kennedy Center provided members of the Association with a model which they used in supporting the authorization of Regional Centers throughout the state. Members of the Parents

and Friends organization participated actively in the process of lobbying, persuading and pushing for legislative changes so that the state would provide more extensive services for the retarded than previously existed. They carried their own example to the Connecticut legislators and to other governmental agency officials and officers of the State in their appeal for the enactment of legislation that would enable the State to establish a state office for mental retardation.

This legislation was passed in 1959, the Regional Center concept followed, but it was not until 1965 that the Parents and Friends own facility, the Kennedy Center, became designated as the Bridgeport Regional Center.

The state conceivably could have provided supplementary financial assistance to the Parents and Friends so that the Kennedy Center could have continued operations as a private non-profit facility rather than as a state facility. If legislation did not provide such support, could not special legislation have been introduced at that time to provide the necessary authorization and funding?

It should be remembered that much of the money to build the Kennedy Center was raised by Parents and Friends in a desire to develop a center independent of state operation and control. Indeed, at the time that the planning occurred for the Kennedy Center, the state was not authorized to run such a facility and the Parents and Friends felt simply that they had no recourse but to develop a program, the best they could visualize at the time, by themselves and with the help of contributions from individuals and organizations in the Bridgeport community.

At the later point, when financial and staffing problems beset the Kennedy Center and affected the completion of payment for construction, would it have been possible under then existing legislation for the state to develop a partnership with Parents and Friends? This could have provided state payment of all or part of the personnel costs, leaving the funds then available to the Parents and Friends for payment of construction costs or maintenance of plant.

If either had occurred at the time, or if other arrangements had been developed, the program could have become a joint arrangement rather than the current situation in which the Regional Center offers and operates certain programs that are increasing in number while the Parents and Friends operates others that appear to be decreasing in number.

The voluntary association known as the Parents and Friends of Bridgeport was and is direct-service oriented. This orientation received emphasis throughout the life of the Project from the sponsors. Its specific service activities, and its efforts to bring about the extension and enhancement of these services, constitute a basic thread of this report.

One must look at these efforts in comparison to how volunteer associations in other communities fared during this time. While simple to formulate, this is a difficult question to answer, for the social organization of the communities in the State vary significantly and the composition, perspectives and resources of the various associations of parents vary as well.

Could other approaches than a federally funded Project have been more successful in

Bridgeport in broadening and intensifying services for the retarded, in bringing about changes deemed necessary? During the period of time covered by the Project, the entire sweep of services provided in many areas throughout the United States was changing. Government was being persuaded or coerced to pay attention to what spokesmen conceived of as necessary services for the retarded.

Bridgeport is considered something of a pioneer within Connecticut. At the least, a number of the active participants in the Parents and Friends Association of Bridgeport felt it legitimate to work very actively in Hartford for the passage of state laws to provide comprehensive services for the retarded through the establishment of the state's Office of Mental Retardation. Through this, the Parents and Friends extended its scope throughout the State. Members of the Board conceived these efforts as appropriate role behavior.

The view of the Board members was that the Kennedy Center provided a case study of how services could be broadened and intensified. Here, the Project played a significant part, for its personnel and efforts during the first two years, were engaged in the development of operations of the Kennedy Center. The Kennedy Center was the creation of Parents and Friends. As a new structure, it added to the formal system of agencies, both private and public, within Bridgeport. It became a focus of services and a system element, concentrating on the retarded, that became part of the environment within the city with which other agencies had to deal. Referrals and consultations to it and from it emerged as a new element within the city.

But how much of an impact the Project made on the development of a new range of community-based services is difficult to establish. Put another way, the establishment of a fixed focus for referrals for a panorama of community services was one of the key objectives of the Project. The extent to which the resources and energies, including those of the Project, were devoted toward the establishment of this focus remains open to question. The extent to which those efforts did in fact produce the desired changes in the organized system of Bridgeport agencies, both public and private, so that parents and relatives came to know where to go for advice, help and suggestions, must also be established.

The construction of the Kennedy Center by the Parents and Friends was a major step forward. Its later takeover by the State as the Regional Center, was another forward step, and in a broad sense this could be labelled a success by the Parents and Friends. What effects the provision of services "for free" to the community by the government agency would have on the Parents and Friends is, of course, another question. Recruitment of members, and the continued participation by existing members might be adversely affected. Some questioned the functions of the parents' organization: "Why join when everything we want and need is already available at the state's Regional Center? "They did the job of getting the State to move in and take over, but that's a thing of the past now."

At another level of government services, the extent of effort by the Project within Bridgeport and the other adjacent communities in its region and the extent of development of additional programs needs to be documented. How much effort was undertaken and with what success? What part did the Project play at various stages in its life in stimulating, encouraging, or catalyzing the several systems to broaden their programs and provide more extensive and more individualized services for the mentally retarded? There is evidence that

this aspect of involvement by the organization with the local government has been less than completely successful and inconsistently pursued throughout the five years of the Project.

As for the Regional Center, the functions at a manifest level included the State government's assumption of operating and fiscal responsibility for programs that had been instituted by the Association. The mortgage was paid up by the State; operating expenses, program development, and operations were out of the hands of the Parents and Friends, at least in a direct sense. Their demonstration that such programs could be operated was completed.

This meant a reduction of their own services. At a latent level, this resulted in a loss of elan, a slowdown in recruiting members, and a change of goals for the Association. With the government operation of the Kennedy Center, the goals shifted to include the maintenance of selected services that could not or would not be operated by the State. These were the two specialized residential centers, the workshop programs, and the program known as Tri-Us.

The community context for goals pursued by a private, voluntary organization is critical for understanding of success. As a single change effort in a single community, the Project is a case study of change. Bridgeport was described by a Board member of the Parents and Friends as a city which was culturally surpassed by New Haven and which obviously did not have the advantages of Hartford, (the state capitol and a national center of the insurance industry). Nevertheless, he observed, it was a wealthy city, with the highest per capita amount of savings bank deposits of any city in Connecticut, and with the resources of the many industries which were located there. Bridgeport itself is known as a highly ethnic community. After New York City, it has the largest urban population of Puerto Ricans in the continental United States. Sub-communities of Negroes, Armenians, Hungarians, Poles, and others exist. Specialized services for youngsters and others from such sub-communities within the Bridgeport population, especially, for example, programs in the schools for those with functional retardation resulting from cultural distinctions in background, could be an appropriate goal for the parents' organization or the State agency.

How extensive is the problem of retardation of such groups? How active a part did the Project play, either in identifying the scope, of that retardation or in formulating and stimulating programs intended to service such segments of the population? To what extent was such an effort a continuing part of the Project's work? Various Association and Project members were active in fact in helping initiate Bridgeport's community action agency, Action for Bridgeport Community Development.

Government was initially being dealt with by a voluntary and private organization, backed up by a Project funded with federally-awarded money. The organizations that served the community were largely governmental; the organization that came into being in time, was the Regional Center sponsored and operated by the State of Connecticut. Their sanctioning basis of legitimacy was the authority of the State, and their responsibility was to the State.

The sanction for the Association was the interest of the parents and the opportunity of such an organization, privately based, to exist in the environment of a free society. Its le-

gal authority was simply to exist, work towards its goals, provided that they were generally acceptable to society, and to do so in accordance with methods considered appropriate by society.

A fundamental issue is the problem of a voluntary parent organization taking on the assignment of trying to stimulate and coordinate the efforts of government agencies, which are responsible to legislative bodies representative of the entire community. One nationally prominent specialist in governmental services for the mentally retarded comments that it simply is not possible for government agencies that are not coordinated with each other, to reach coordination through the sponsorship of a voluntary organization, parents or otherwise.

Tangible goals were exemplified by the takeover of the Kennedy Center building by the State. Success in attaining that or any tangible goal required the formulation of additional less tangible, more remote goals. In terms of the sponsor-implementer distinction already outlined, the parents, as sponsors of change, formulated tangible goals and recruited implementers to accomplish them. The Project staff and professionals as implementers of change who came on the scene, had to formulate other, intermediate goals, necessary in their eyes for the attainment of the tangible goals.²

After the Regional Center was established, the goals of the implementers shifted to required outside resources, for the sponsors saw their own key goals fulfilled by the Regional Center and felt their own resources had yielded the desired outcome. Since many efforts were now to be undertaken by a governmental agency, the Project as a resource of the Association could now be used for other purposes. These included continuation of the workshop, the stimulation of other governmental and private agencies, such as the YMCA program, and the Tri-Us program and residential facilities which were directed and operated by the Parents and Friends. The Sheltered Workshop had moved out from the physical setting of the new Regional Center. The program that later developed into Tri-Us was anticipated in embryonic form through the involvement of its Director with the Kennedy Center and her employment there, but was set up operationally through the subsequent award of a USPHS Division of Chronic Diseases grant (terminated after two years).

² Implementers come equipped with remote and visionary unrealistic goals, in the thinking of the sponsors. Either sponsors or implementers may have their heads in the clouds, sponsors because they are too visionary, perhaps with conceptions that are impractical and unlikely of fulfillment in the specific setting, and implementers because they may not understand fully the possibilities sanctioned by the local culture. They may arrive with ideas that worked elsewhere where resources may have been more extensive or at least quite different. Implementers and sponsors often fail to clarify their goals and of means or to explain them properly to each other.

With the establishment of the Regional Center and the taking over of the building from Parents and Friends, a reduction of the direct-service involvement by Parents and Friends occurred. While the Regional Center came into existence, its service area mandate primarily covered day care for young retarded, ages six to twenty. Workshop activities and residential services were outside its range and day services for the severely retarded were not emphasized. These became the new work of the Association, and the Project was viewed as an aid to that work. While the Regional Center was not intended to duplicate existing services in the community, its legal mandate covered all the retarded.

As an affiliated unit of the National Association for Retarded Children, the Parents and Friends were well aware of the Fettinger Report (October 9, 1958), which stated that the aim of the Parents' Organization was "to obtain, not to provide". Yet the Parents and Friends have maintained a continuing commitment to operations, while at various times cajoling and influencing other organizations to take over responsibility for service programs they once initiated. This interaction between demonstration and operation has continued through the years and has provided recurrent problems, challenges, and threats to the Association's actions and to the efforts of the Project.

CHAPTER XI

CONCLUSIONS: THE REALITY OF THE ATTEMPT AT THE PURSUIT OF CHANGE

The Association has tried hard to do more for the retarded. For that effort, it deserves credit. The effort itself focused on innovations in areas that had not been experienced or explored in the same fashion by other associations. Accordingly, mistakes and failures have been recorded while advancements have been made. This record is complicated but it is a record of effort where others have not attempted such changes or where full accounts of other efforts, as presented here, have not been prepared or released.

The willingness of the Association to permit a detailed report of its activities during the last five years illustrates its innovating characteristic, its desire to provide service and to share its experiences with other groups. Thereby, this report serves the retarded and is itself part of the long record of contributions by the Parents and Friends of the Mentally Retarded Children of Bridgeport, Inc.

We review here the entire list of specific sub-projects identified in the original proposal (Chapter III), and judge the current state of reality of each of the many sub-project ideas. In particular, we compared the idea for the sub-project as presented in the Proposal with the relevant features of events and structures existing within the community today.

We asked for each item the following questions:

- (1) To what degree was the initial objective achieved?
- (2) Did any new or changed patterns of services, as advocated in the statement of the sub-project in the Proposal, come about as the result of the Project?

The Project Writing Staff first selected from the list of sub-projects those for which there is evidence that the sub-project as initially formulated (1) was specifically undertaken, (2) was achieved in full or in part, and (3) was the result of the Project.

We present below a list of those sub-projects which in our judgment fulfill these criteria and thereby represent specific accomplishments of the Project. We have made no attempt to ascertain the relative importance of these achievements.

List of Achieved Sub-Projects

Facilitate the integration of the "marginally independent" retarded in society, including vocational rehabilitation and selective placement in regular employment.

Establish dynamic community residence centers, short-stay facilities and half-way houses.

Involve public health nurses in retardation services.

Strengthen the state association (CARC).

Provide director of adult services, social worker, clinic director, service specialist, part-time community relations specialist.

Expand recreational programs.

Demonstrate the role of the local association.

Define the variety of adjunct and vocational services for the mentally retarded.

Conduct research on state institution referrals to the community for rehabilitation. (Other limited research, especially attitude surveys, was undertaken.)

Develop and continue cooperative relations with:
Office of Mental Retardation
Bureau (now Division) of Vocational Rehabilitation.

The above list represents the specific areas where some degree of achievements resulted from the efforts of the Project per se in attempting pointedly to implement the formulated ideas for sub-projects presented in the Proposal.

The second list is of those sub-projects where there is evidence in the detailed examination of the records and operations that (1) the sub-project was attempted, and (2) the sub-project appears not to have been adequately sustained for a sufficient length of time or with sufficient effort to be considered "accomplished" in full or in part to the extent or in the manner outlined in the Project's Proposal.

List of Attempted But Unfulfilled Sub-Projects

Create greater citizen participation.

Recruit and train volunteers.

Involvement in a comprehensive services plan of the following Agencies: Family Service Agencies, Y.M.C.A., Y.W.C.A., Child Guidance Clinic, Homemaker Service, Goodwill Industries, Bridgeport Sheltered Workshops.

Demonstrate the effectiveness of a basic vocational evaluation and training unit for determining vocational service needs and creating community vocational services.

Provide professional counseling for parents.

Provide home counselors.

Organize volunteer and professional training seminars and workshops.

Encourage inclusion of retarded in hospital services, covering early identification and counseling.

Establish parent education and counseling programs to be established with family service and child care agencies.

Improve services and activities for adult and aged retarded persons.

Provide comprehensive publicity and public education in all mass media.

Develop brochures and bulletins for communication.

Conduct attitude surveys on mental retardation.

Prepare a directory of services.

Develop informational "kit".

Organize community and professional lecture series concerning retardation to be sponsored with local universities and agencies.

Organize regional workshops and seminars on mental retardation for public health nurses and vocational counselors.

The third list below includes those items drawn from the entire list of sub-projects which meet the following criteria:

- (1) insufficient evidence exists that it became operational in any form at all;**
- (2) insufficient evidence exists that the Project's efforts led to it becoming operational or established;**
- (3) insufficient evidence exists that if operational it became a typical and recurrent feature of the structures of services for the retarded; or**
- (4) no evidence exists that it was in fact attempted.**

SUB-PROJECTS THAT WERE NOT ACCOMPLISHED

Initiate research and professional training.
Develop guardianship plans and legal assistance programs.
Enhance inter-agency relationships.
Initiate and operate a systematic recording keeping procedure to follow individual retardates along the continuum as well as maintaining a history of developing relationships between community agencies.
Establish an information and referral service.
Encourage development of pre-school classes.
Re-evaluate criminal responsibilities of defective delinquents and study the best means of helping and caring for such individuals.
Help in the choice and administration drug therapy for those individuals who need it.
Provide special help with dental problems.
Provide corrective measures for improving speech, hearing, sight defects.
Develop nursery classes (with normal children when possible).
Extend special nursery classes.
Expand day care centers for the severely retarded.
Provide special educators with improved vocational training for the educable.
Provide special educators with improved social training for the trainable.
Establish vocational training centers and sheltered workshops including personal adjustment training and terminal employment opportunities.
Establish community centers with recreational, social and counseling facilities for the adolescent and retarded adult.
Demonstrate the role of a "project staff".
Demonstrate the vital role of public relations, community relations and public education.

Demonstrate the effectiveness of the joint efforts of volunteer laymen and professional workers in planning and implementing a comprehensive model of services.
Plan reorganization and extension of existing facilities.
Establish community diagnostic-treatment clinics.
Establish procedures for foster home care through public welfare and child caring agencies.
Establish a "Career Opportunities Program" for recruitment of retardation professionals.
Establish K.C. as professional training center for social science disciplines by opening student training, research and field work relationships with professional schools.
Establish major control groups for evaluation of demonstration project.
Conduct research comparing cases served by the diagnostic clinics in Bridgeport, Hartford and New Haven.
Conduct research comparing cases handled by B.V.R. in the three cities.
Conduct research of cases referred during a ten year period to the state institutions from the three cities (including the five years of the project).
Conduct research on cases passing through the three clinics over a ten year period.
Arrange for and utilize pilot studies by Bridgeport Public Schools; New Haven Community Progress, Inc.; Bridgeport Hospital; and Southbury Training School.
Conduct attitude surveys among parents of retarded in community residence.
Conduct surveys dealing with operations of diagnostic clinic, social agencies and the Project staff.
Utilize research by Fairfield University sociology Department on work aspira-

tions among the Puerto Rican population.
Utilize findings of Project REACH on school drop-outs.

Conduct research on interactions between community and Project, between Project and agencies, and between professionals and lay volunteers.

Organize leadership training workshops for volunteers.

Furnish visiting services to other communities.

Provide consultation services in:

- Recreation
- Community Organization
- Vocational Counseling
- Research.

Utilization of the following agencies or individuals in evaluating effectiveness of the Project:

- Office of Mental Retardation
- State Office of Education
- Southbury Training School
- Superintendent of Schools,
School Board
- School Board Member
- Community Profess, Inc. New Haven
- Bridgeport School Psychologist
- United Fund and Community Council
- University of Connecticut School of
Social Work

- Fairfield University Sociology Dept.
- Fairfield University Psychology Dept.

Develop and continue cooperative relations with:

- University of Bridgeport School of
Nursing & Secretarial Division
- Southern Connecticut State College
Special Education Division
- Southbury Training School
- State Welfare Department
- State Park & Forest Commission
- State Department of Health
- Bridgeport Hospital
- St. Vincent's Hospital
- City of Bridgeport Division of Human
Affairs
- Crippled Children's Workshop
- Cerebral Palsy Center

Bridgeport Speech and Hearing Clinic
Bridgeport Volunteer Bureau

Enhance Communication, cooperation and coordination between professional disciplines and volunteer groups.

Make effective use of local universities.

Develop techniques by which cities and towns plan and work together.

Develop a basic regional plan.

Structure and develop day care services in outlying communities and relate day care services with other community agencies such as hospitals and home care programs.

Facilitate practical implementation of research findings by organizing research as part of comprehensive community services model.

Perspectives and Issues

Perspectives overlap in planning for action and in the action itself throughout the history of any human endeavor and this occurred during the course of this Project. We have attempted to avoid judging any perspectives as "right" or "wrong", "good" or "bad", "helpful", "constructive" or "destructive". We have attempted at various times to explain why certain perspectives were held by certain groups or individuals.

We have been guided throughout by the presupposition that perspectives represent efforts by individuals and groups to cope with problems in the environment. Definition of what problems exist are of course themselves subject to variant interpretation, and this also reflects perspectives. What is seen as a problem or as a threat by one individual is often not so described by others. We avoid any conclusion about the relative sincerity of any of the actors in the complex history of the Project and assume that all were and are sincere.

At the same time, we have a bias in presenting the material, for which the formulation of E. G. Boring may serve as a capsule summary. Boring said, "Enthusiasm is the friend of action and the enemy of wisdom." How this applies to the varying issues summarized below remains for the reader to determine.

The Change Issues

Major problems that have emerged during the course of the five year Project raise the following questions of broad general interest about the degree and effect of change, and the pursuit of change:

1. Can a systematic program of change be sustained over an extensive period of time.
2. Can a widely acceptable and appropriate assignment of priorities be developed for specific areas where change is desired by supporters of, participants in, and onlookers to, a focal group.
3. Can sponsors for change and implementers for change maintain effective contacts with each other.
4. Can a program for change in activities of a variety of independent organizations be generated on the initiative of a single organization in the set.
5. Can change occur without a careful and objective prior analysis of the structure and function of existing organizations, so that the base of effort in the community at large is known.
6. Can strategies for change be left for granted or for later improvisation, or must they be planned in advance with suitable leeway provided for the conceivable development of

alternative strategies for diverse situations and organizations.

7. Can the establishment of a single focal organization for the instigation of change in a multi-organization set be in fact a functional strategy for inducing change, or support for specific change programs in a number of organizations more likely to be more effective.
8. Can the responsibility for changing organizational activities and relationships be properly assumed by one or more organizations that have pre-existing and continuing commitments, investments and interests.
9. Can a single organization of citizens acting in a private capacity effectively bring about changes in activities of organizations that are part of governmental systems.
10. Can an organization concerned with change develop coherent, effective and realistic program of innovations for which few or no guidelines exist.
11. Can a change-oriented Project dependent on and sponsored by an existing special-interest-focused and service-providing group bring about (1) change in the sponsoring group, (2) change in other organizations, and (3) links between sponsors and the environing organizations.

The Community Issue

As a goal, a program for the pursuit of change in community structures and for the greater interaction and involvement of organizations with community groups and individuals requires (1) basic understanding of gaps, unfulfilled expectations and needs where existing organizations fall short, (2) preparation of detailed objectives for change in these patterns by the change-initiating and change-implementing groups, and (3) determination of functional strategies and tactics to develop current reality into the anticipated utopia.

Such a change program requires (1) a survey of existing service programs of organizations and agencies, (2) a review of needs, (3) an analysis of under-used resources or potential resources that can contribute to the fulfillment of the defined needs, and (4) the formulation of an overall plan for using existing organizations, strengthening such organizations where appropriate, and creating new organizations that are considered necessary.

A powerful and subtle effort is required to involve other organizations in a community, so that their normally-independent goals, programs and efforts can combine in some integrated and reasonable fashion, and can reflect appropriately usefully, and in adequate degree the new elements of program for which change is sought.

Descriptions of the overall operations of other organizations, including infringement upon prerogatives of determining priorities for and directions of effort, are common enough so that the likely consequences can be identified. The most frequent effects are antagonism, hostility and resistance.

Levels of involvement range from (a) simple recognition of changes desired, (b) some just noticeable difference in the activities undertaken, (c) some re-casting of efforts of personnel and sub-units, to include a planned involvement in the new area, and (d) some additional involvement of the organization that is appropriate to, but not descriptive of, its obligations to its own goals and sponsors.

Awareness of unfulfilled expectations may lead to demands upon organizations that are realistically likely to bring about resistance. Moral indignation may lead to the formulation of demands that cannot be fulfilled by other organizations except at the price of subservience. Denial of such demands may re-enforce the initiating moral indignation, but the same end result can follow from the partial inciting and meeting of demands.

The Project was administratively part of a special Association which would naturally be concerned about its own aims and those of its membership. To these aims were added the Project goals of developing community agency interest and services for the retarded.

The Association's perspectives on such activities and events were Association-centered and internally focused. A confusing element involves the question of orientation to the mentally retarded being served. Specifically, how wide was the scope of the Project? Was it established to function mainly through an extension of existing services and an enrichment of what already existed for the benefit of prior clients? Was it established to generate new systems of identification of the mentally retarded in the larger geographic area, whether or not affiliated through parents with the Association, to mount new types of services for this possibly large group, and to encourage other agencies to take all the retarded into their programs of effort?

A further compounding perspective concerns the public aspect of the Project. Government funds were made amply available to a project to demonstrate community-based services for the retarded through the testing of a new "model". A public interest existed throughout, and this served as a potential, if not actual perspective toward the responsibilities which were assumed when the Project was funded by the federal agency.

A key part of this Demonstration Project would involve the Parents and Friends Kennedy Center; but it appears to us that the basic thrust of the Project lay outside current programs. The Kennedy Center programs already existed and were substantial, particularly in comparison with the level of organized effort for and on behalf of the retarded at an earlier date.

In the absence of some form of a Community Advisory and Review Group for this Project to whom the Project Director would be responsible and from which he could receive (1) support (2) guidelines focusing on a blueprint of Project aims and (3) priorities concerning the Project's aims in the community, its effectiveness is unclear. What methods, resources

and efforts were being undertaken and how they were to be evaluated, the successes and failures, the timing of changes, could not be readily and regularly appraised, given this lack.

It appears that the Project did not consistently, effectively, and efficiently pursue its aim of generating a model or full use of existing or new community services by organizations in the community. The problem and aim faced by this Project was to go beyond, far beyond, what already was operating.

A project agency, outside the jurisdiction of a single group directing and operating a current service program center, might have better been able to focus on the generation of new services, to generate interest in new types of services and to gain the support of other groups and agencies in the community whose interest and participation had to be secured.

The issues entailed can be formulated in the following question: Can a limited membership group effectively house and sponsor a community-wide and based organization which has the objective of change?

The Professionals-Parents Issue

Relationships between professional staff and parents is another important problem area.

Trust between the two groups appears overall to have been weak and less than desired. Parents were unwilling or unable to accept the capabilities of the professionals, and the professionals were equally unwilling or unable to understand fully the intensity of the emotional concern of parents. Later phases of the Project saw a lessening of this confrontation, but by that time many professionals had withdrawn from participation in the Project and a pattern of alienation had become established.

With strong but considerate professional leadership, this problem could have been minimized. One solution would have been to establish a Community Advisory Review Group with representatives of community agencies, professional staff, parents, public agencies, business and industry. This committee would have overseen and evaluated professional-parent relationships, fielding complaints and suggesting solutions. Its constant task would have been to prevent divisiveness from intruding on the betterment of community resources for the retarded.

The Staff Issue

The staff of the Project were it seems, hired to perform a range of duties that sometimes submerged their responsibilities to the Project. Insufficient orientation to aims of the Project, insufficient encouragement, and lack of assignment of specified amounts of worktime to be devoted regularly and systematically to community-based activities: all these had a negative effect on the outcomes of the Project. It appears from the records that insufficient involvement in community agencies was exhibited by many staff persons.

"We lost our contact with the community" was clearly stated by many once pioneering parents. They had in the beginning a purpose, cause, and function to develop and provide services; during the early active period of the Project's endeavors, the parents' efforts were replaced by those of the professional staff. Many parents feel that this detached them from a direct role in the community.

Bringing in new Association members came to be seen as less critical. When there was something to do, the reason for active recruitment existed; as professionals came in, the necessity for this dwindled. The sense of cause, purpose and function waned, and a decrease in enthusiasm and in new recruits followed inexorably.

Summary Assessment

- What did the Project accomplish?
- What did it fail to accomplish?
- How did it achieve what it did?
- What problems limited the extent of achievements?

We attempt below a summary assessment of overall achievements and failures of the Project.

First the achievements.

Achievements

The Project was successful in that it:

1. stimulated the secondary school program of work/experience training.
2. extended at least for a time the range and integration of services for the retarded in the Bridgeport area.
3. stimulated a local Y.M.C.A., a general community service agency, to include the retarded in recreational services.
4. helped maintain and broaden through staffing funds, the program of consultation available through the state Association for Retarded Children to local Association chapters.
5. helped prepare applications for additional grants by state and federal agencies covering the extension and improvement of specialized rehabilitation services for the retarded centering on the workshop and on a program for the "training and rehabilitation in useful service" (Tri-Us).
6. facilitated the use of specialized services by a state rehabilitation counselor assigned to the sheltered workshop.

7. initiated, for a time, a pilot satellite workshop in a "branch" community.
8. initiated a joint school-recreation program in Trumbull and Fairfield that brought together the efforts of the schools and the local Y.M.C.A.
9. generated publicity regarding the retarded, their needs, and programs of benefit to them.
10. contributed to the opening and current operation of group residential homes.
11. was instrumental, along with numerous other agencies and individuals, in speeding up the decision by the state's Office of Mental Retardation to locate a Regional Center for the Retarded in the Bridgeport area.
12. initiated some greater involvement by Public Health Nurses with the retarded, through in-service training focusing on case-finding and parent counseling.
13. contributed to the maintenance and continuation of Association activities undertaken prior to the Project, including clinic programs, sheltered workshop, day care, camping, recreation, and speech therapy.

Many things were attempted and without question some contribution to the retarded was made. It is, however, the judgment of the writers that much more could have been accomplished, with more lasting effect, if the Project had attempted to develop new models to bring about more innovative changes, rather than focusing to such an extent on the specific operations of pre-existing services.

The judgment we have reached is that the community did not become involved in any significantly different way with the retarded as the result of the Project. Some alienation from professionals and from other service agencies has occurred. For the money expended, the results appear small.

A planned sequence of change, development, growth, innovation, and expansion was not developed and pursued during the lifetime of the Project.

Bridgeport in 1969 does not enjoy a significantly different set of services for the retarded, whether operating under the aegis of the Parents and Friends or of the state Regional Center for the Retarded, than would exist had the Project not operated.

There appear to have been only two or three specific major or minor innovations in programs and staffing, initiated and operated by the Project and its sponsoring Association, which served as convincing demonstrations to other agencies and groups, so that they took over the innovations and came to operate them as a regular part of their own programs.

Non-Achievements

The Project was not successful in:

1. the demonstration of comprehensive mental retardation services as proposed.
2. the integration of community-based services and the fullest possible use of community resources to serve the retarded.
3. the achievement of its aim of moving Bridgeport noticeably ahead in the provision of services for the retarded than (a) the community would have reached without the Project and (b) other communities have reached without the benefits of such a Project.
4. the enlistment of the continued participation of professionals in its own programs, in programs of other agencies, in on-going direct services and in community activities required of the Project in its proposal.
5. the sharing of responsibility between those offering direct services and those outside groups offering generic services.
6. the integration of the programs and services related to or controlled by the Association with the needs of the community as determined by careful, systematic evaluation of the emergence of problems in the community and its population groups.

Implications

And now we turn to the implications of the five years of efforts and undertakings, achievements and failures, problems and accomplishments.

The Project Writing Staff has arrived at the following list of items that emerge from the experiences of the Project that may serve as pre-conditions and requirements for similar efforts to pursue change elsewhere:

1. Careful preliminary analyses of community structures, power bases, decision making processes, social organization, and interest groups prior to efforts to initiate change.
2. The necessity of maintaining a continuing focus on obligations to the community.
3. Establishment of a Community Advisory Review Group, including representatives of the sponsoring association, community agencies, business and industry, state and local governmental bodies, to participate in planning, evaluation and review of efforts of such a Project, to whom it would be responsible.

4. The establishment of independent power, responsibility and authority for such a Project and its staff, with advisory roles for other groups including Association, its Board and its committees and outside groups.
5. The statement of specific procedures and priorities for change, including a time-table and an allocation of specific sums of money.
6. Careful and periodic re-assessment of behavioral accomplishments and failures in terms of efforts expended and priorities placed.
7. Allocations of specific sums of money for particular sub-programs with periodic checks and systematic evaluations of what has been accomplished and what remains to be accomplished.
8. Avoidance of the statement of grandiose goals, so general and idealistic that:
 - a. The likelihood of an ability to work on all these goals is minimal or absent.
 - b. The likelihood of developing a coherent, acceptable, and effective priority ranking of these goals is minimal or absent.
9. Avoidance of the formulation of objectives that appear desirable but where specific behavioral outcomes cannot be clearly delineated.
10. Efforts to deal with beliefs that sponsoring parents "do" and others such as professionals "exploit".
11. Efforts to deal with beliefs that existing organizations and "the establishment" in general are not capable of change or of services for specialized sub-groups.
12. Mature management of beliefs about:
 - a. The necessity of fighting the establishment as group members sponsoring change believe they once did.
 - b. Defining professionals as callous, indifferent, calculating, a necessary evil, and outsiders to a socially significant and emotionally critical enterprise.
 - c. Defining sponsors and parents as emotionally motivated, likely to intrude into technical and professional domains, short-sighted and beset by personal problems.
13. Maintaining a constant process of accountability for the use of time, staff and effort to move toward goals, and evaluating the efficiency and effectiveness of these efforts.

14. Minimizing distrust of parents, laymen and volunteers by professionals through
 - a. systematic in-service training
 - b. initial orientation and effective communication
 - c. avoidance of grapevine indoctrination, and
 - d. use of laymen in policy formulation.
15. Minimizing distrust of professionals by parents through
 - a. clarification of goals
 - b. effective communication
 - c. clear assertion of program direction
 - d. maintenance of professional job security, and
 - e. appropriate use of parents in program operations and planning.

APPENDIX I

PARENTS & FRIENDS OF MENTALLY RETARDED CHILDREN OF BRIDGEPORT, INC.

1135 William Street*

Bridgeport, Conn.

A SUMMARY HISTORY OF KENNEDY CENTER*

Our organization is named the Parents & Friends of Mentally Retarded Children of Bridgeport, incorporated on April 11, 1951. At the time the agency started functioning, it was a parent sponsored group, and continues to function in this manner. Our Board of Directors is made up of 16 members, 15 of whom are parents. The first objective of the parent association was to create trainable classes for the retarded of Bridgeport. This was accomplished with the cooperation of the Superintendent of Schools, and in 1951 the first class in New England for trainable children started in Bridgeport. Since that time 9 more classes have been added, with a total of 120 children enrolled.

Our next objective was to provide a recreational program for adults in the community. In cooperation with the Board of Recreation these classes were started one evening per week in a local school gymnasium, and have continued ever since. During the summer these classes are held outdoors in one of the local parks.

In 1954 the organization decided that there was a need for a community center for retarded children unable to attend public schools, or not otherwise served in the community (we know now, after a study by the State Legislature, that there are an estimated 40,000 mentally retarded children and adults in the State of Connecticut). With \$6,000.00 in the bank, a piece of property was purchased and the actual design, and 70% of the physical labor involved was done by parents of the association. Within 15 months the building was completed and in January, 1956, a program was started.

The organization became a member of the United Fund in Bridgeport in 1955, and hired its first professional employee, the Executive Director. In January of 1956 when the Center opened for 30 children between the ages of 3 and 18, the total staff was an Executive Director, a Nursery School Instructor with no previous experience, and a contractual driver and rented station wagon for transportation purposes.

Immediately following the opening, the next step in the creation of comprehensive services was a diagnostic clinic. This clinic was started through the volunteer services of a physician-surgeon, a member of the Board, and through contacts made by him, a volun-

* This item, from association files, was dated June 1960.

teen pediatrician, a volunteer psychologist, and laboratory services at cost, were obtained to do diagnostic evaluations of known and suspected mentally retarded children and adults. The Executive Director acted as the administrative officer of the clinic and also did Social Service Intakes. Since that time a psychiatrist has been added, a paid part-time psychiatric social worker, a volunteer dentist, 2 psychological examiners, a clinic secretary, a speech therapist, 2 volunteer social workers for home visitations, and 4 medical specialists, including a neuro-surgeon who provides electroencephalograms. This diagnostic clinic is the base of our operation. All known or suspected mentally retarded children and adults must first be seen in the clinic before any program is developed for them. The clinic not only does the evaluation, but refers to the family physician for treatment and also to various programs for service. There is also an attempt to follow up each child or adult 3 times within a 5 year period. In addition, the services available under our jurisdiction provide observational reports for the clinic team to evaluate.

Programs presently in operation are as follows:

Pre-School - 3 to 9 years of age
31 Children, full day 9 - 4 program

Junior Day-Care - 3 to 14 years of age
24 Children, full day 9 - 4 program

Senior Day-Care - 14 years of age and up
12 enrolled, full day 9 - 4 program

Vocational Rehabilitation & Sheltered Workshop
- 16 years and over
24 enrolled, full day 9 - 4 program

Speech Therapy - 68 enrolled, 1/2 hour per week, all ages.

This is considered our 5-day week program. In addition to this, we participate in a religious education program for Catholic and Protestant Children, and are presently developing a Hebrew program. We also conduct an evening program consisting of:

Activities of Daily Living Class
Craft Shop
Girl Scouts
Explorer Scouts
Teen Club
6 weeks Day-Camp
9 weeks Resident Camp

We also conduct cooperative programs with Cerebral Palsy where we have severely retarded cerebral palsy children participating in a 5-day week program from 9:00 to 2:00, and at present 4 children are enrolled. As of June 4, 1960 we initiated the first group therapy program for high-grade retarded children, 7-12 male, in conjunction with the Bridgeport Child Guidance Clinic. In addition to the group therapy program for the chil-

dren, under the supervision of the Child Guidance Clinic, we conduct a group therapy program for the parents through the services of our psychiatric social worker. The other aspect of our program is the involvement of parents in activities associated with the public education, community relations, and public relations of our organization. We conduct 41 subcommittees made up of parent members, publish a monthly bulletin, and utilize the parent in every type of service job possible. Included in this are dessert-and-discussion sessions where subjects are covered of general interest to the care and rearing of retarded children.

In cooperation with Southern Connecticut State College, Department of Special Education, we present demonstration classes of children to student teachers.

We also conduct an active volunteer program and have with us 26 non-parent of retarded children volunteers who give either part, or a full day in working with the teachers in the classrooms. In addition, we have a working agreement with Bridgeport Hospital and the University of Bridgeport, School of Nursing, where nurses in their pediatric year spend 3 days working at the Center, under supervision, to learn the problems and handling of mentally retarded children and adults.

We have recently initiated 2 research programs for which we hope to get approval from federal agencies. One is a program presently in operation in conjunction with the Trumbull (a local community) Board of Education. This program is designed to provide a team diagnostic evaluation of students in the public schools for placement in special classes. It also includes statewide curriculum planning committee whose objective will be to develop an on-going curriculum for trainable and educable children so that a comprehensive and coordinated program can be designed and implemented within the public school setting. Also involved is a vocational counsellor who will be available to the students on a high school level for potential job placement and follow-up. The other project is an investigation of sibling-parent-retarded child relationship. We have discovered that most diagnostic clinics see only the retarded child and his parents. We feel this is a definite oversight, and are presently initiating a program to interview the siblings of retarded children to determine their involvement, problems, acceptance and rejection of the child, and how it affects their functions.

Our next step is the creation of a new building 3 times the size of our present facilities, for which an architect has been hired, and the projected date of occupancy will be Easter, 1961. In association with this new building will be the development of residential facilities for the retarded who does not need institutionalization.

All this is in conjunction with the new laws which have been passed in the State of Connecticut. The 1959 Legislature passed the following statutes to benefit the retarded children and adults:

1. Mandatory education for trainable and educable children between the ages of 6 and 21, effective September 1961.
2. An office of mental retardation in the State Department of Health, with a Deputy Commissioner of Health for this office.

3. This office is charged with developing and supporting community programs for the retarded in the State in day-care centers and vocational training programs. In addition, the office is responsible for supporting 3 diagnostic clinics for the retarded, as well as supervision of the 2 State training schools.

All these services in our community will be developed in conjunction with plans presently in formulation in the Office of Mental Retardation. These plans include 3 community residential facilities to be constructed in the State with a maximum of 300 beds each.

Connecticut has come a long way within the last 10 years, and the plans under formulation are both exciting and inclusive.

The preceding information is an actual recount of the services presently provided by the Parents and Friends of Mentally Retarded Children. I do not believe that I have conveyed the dynamic function of the organization which in reality cannot be described on paper. All of these services are provided by 23 full or part-time staff people, some with experience in the field of mental retardation, others trained through in-service training programs. I hope this information will be of some value to you, and assure you that a comprehensive program can be made to work. We have found by asking "ye shall receive". All this is being done at present on an \$80,000.00 budget, \$36,900.00 being provided by the United Fund, the remainder raised in gifts and fees. If you have an opportunity to visit us, we would be more than happy to have you see for yourself what has been done when "one community cared enough to do the very best".

June, 1960

APPENDIX II

DESCRIPTION OF PRESENT OPERATIONS OF THE KENNEDY CENTER*

1. A Summary History of Kennedy Center

The organization is named Parents and Friends of Mentally Retarded Children of Bridgeport. It was incorporated under the laws of Connecticut on April 11, 1951. It is non-profit and tax free. At the time the agency started functioning it was a parent sponsored group and continues to function in this manner. The Board of Directors is made up of 17 members.

The first objective of the parent association after it was organized was to create trainable classes for the retarded in Bridgeport. This was accomplished with the cooperation of the Bridgeport Superintendent of Schools, and in 1951 the first class in New England for trainable children was started in Bridgeport.

The second objective was to provide a recreational program for retarded adults in the community and a program was started on cooperation with the Board of Recreation of the City of Bridgeport.

In 1954 the organization decided that there was a need for a community center building for retarded children who were unable to attend public schools or who were not otherwise served by some other program in the community. With \$6,000.00 in the bank, a piece of property was purchased on William Street, Bridgeport. The actual design, and 70% of the physical labor involved in construction was done by parents in the association. Within 15 months the building was completed and in January, 1956, a program was started in the Kennedy Center.

The organization became a member of the United Fund of Eastern Fairfield County in 1955, and that same year hired its first professional employee, an Executive Director. In January of 1956 when the Center opened for 30 children between the ages of 3 and 18, the total staff consisted of an Executive Director, a Nursery School Instructor with no previous experience, and a contractual driver who drove a rented station wagon for transportation purposes.

a. Diagnostic Clinic

The next step in the creation of comprehensive services was to organize a Diagnostic Clinic. This clinic, opened in 1956, was started through the volunteer services of a physician-surgeon who was a member of the Board, a volunteer pediatrician, a volunteer psychologist, and laboratory services at cost. The purpose

* This item was prepared in 1963 and was included in the Project Proposal dated October 1963. Pp. 36-40.

was to do diagnostic evaluations of known and suspected mentally retarded children and adults. The Executive Director acted as the administrative officer of the Clinic and also did Social Service Intakes.

Since that time, a dentist, a speech therapist, a social worker, a vocational counselor and a number of medical consultants, including a neuro-surgeon to provide electroencephalograms. This diagnostic clinic is the base of the operations. All known or suspected mentally retarded children and adults must first be seen in the clinic before any program is developed for them, or before they can be admitted to any Center program. The clinic not only does the evaluation and diagnosis but also determines the individual's management program and makes the necessary referrals to either a Kennedy Center program or to another community agency for service. Referrals also made to family physician for an indicated treatment. There is also an attempt to follow up each child or adult 3 times within a five year period. In addition, the various programs of the Center provide observational reports for the clinic team to use for evaluation, diagnosis and prognosis. The Clinic has no geographical boundaries since it is state affiliated operation. All but few cases, however, are from southwestern Connecticut.

b. Programs

The Center sponsors several full-time training programs for the mentally retarded of all ages. These programs are held five days a week, six hours a day, fifty-two weeks a year. Each program is under a person highly-qualified to supervise and carry out the program to which he or she is assigned. Since the programs are supported in part by Community Funds and that there are other associations for the retarded serving nearby communities, participation in all but the Diagnostic Clinic is limited to seven towns as follows: Bridgeport, Easton, Fairfield, Milford, Monroe, Stratford and Trumbull. A brief description of the full-time programs is as follows:

PRE-SCHOOL: Children from 3 years of age and up who through Clinical diagnosis show potential for attending public school classes in the near future. Transportation and hot lunch is provided. Purpose is to prepare the child to meet the eligibility requirements for public school in any one of the several communities served by the agency.

SENIOR DAY-CARE: Program is for children 3 years of age through adulthood. Purposes are to train them to take care of themselves and for eventual attendance in another program at Kennedy Center or in the community. Transportation and hot lunches provided.

VOCATIONAL TRAINING PROGRAM: This program is both vocational training and for sheltered employment. It is for retarded individuals 16 years of age and up. A full day program to prepare persons to get and retain gainful employment in the community. Work experience is through sub-contract work obtained from local businesses and industries. Clients are paid on the basis of their performance through piece-work. Food preparation is also a training opportunity and hot lunches prepared for all programs is done here. No transportation provided as situations are created as close as possible to those in the community.

SPEECH THERAPY PROGRAM: For individuals of any age who can be aided by speech therapy in their habilitation of training programs. Program available to children attending Kennedy Center and public schools.

SOCIAL SERVICE PROGRAM: A full-time family counselor is available to assist families with any problems they may have relative to their retarded child. The Counselor serves as a liaison between the family and the Center or the community. The Counselor is available to any family to help and advise them in getting assistance to work out or avoid problems.

In addition to full-time programs, Parents and Friends sponsors a number of specialized programs and activities for all retarded individuals. These programs are as follows:

RELIGIOUS CLASSES:

Catholic: Held each Saturday morning during the regular school year. Instruction given in preparation for Confession, Communion and Confirmation.

Protestant: Held every other Saturday during the regular school year. Instructions on leading a Christian life.

Hebrew: Classes organized to meet the need on basis of number concerned.

CRAFT SHOP: Evening session weekly at Kennedy Center for boys capable and interested in woodworking and making wood articles. Fathers invited to attend and work with their sons.

GIRL SCOUTS: Combination Girl Scouts and Social Hour. Meet weekly at Center during public school year. Emphasis on socializing and group-activities.

EXPLORER SCOUTS: For older boys interested in Scout activities. Meets weekly at Center except in summer.

PLAY THERAPY: A specialized program for a small group selected by Diagnostic Clinic under supervision of play therapist. Held weekly, year round, at Center.

SUMMER DAY CAMP: A six weeks day-camp for children attending public schools. Transportation provided. Professional supervision. Planned program of social group activities, crafts, music, games, etc.

RESIDENT CAMP: Resident Camps for a nine-week period each summer at Camp Harkness. Sponsored by Connecticut Association for Retarded Children. Arrangements made through local unit.

RECREATION: During the year, a number of recreational activities are held such as bowling, picnics, baseball, dances, Christmas parties, and visits to other local associations for dances, etc.

2. **Agency Relationships**

Kennedy Center is used by a number of educational, medical and community agencies

as a "training ground" to familiarize their people with the retarded individual and what problems may be encountered in dealing with them. University of Connecticut School of Social Work assigns graduate students to get their field training experiences at the Center. Schools of Nursing at Bridgeport Hospital, St. Vincent's Hospital and University of Bridgeport, require each student nurse to spend three days of their pediatrics training working with and observing the children at the Center. Classroom demonstrations are given to students and teachers working on advanced degrees at University of Connecticut and Southern Connecticut State College. University of Bridgeport also uses the Center for field training of girls in the Secretarial College. Many social agencies such as VNA's, Family Service, State Welfare, have their staffs make periodic visits to the Center.

In order to bring about comprehensive programming, Kennedy Center integrates with all community agencies offering assistance to the individual. Close liaison is maintained with all public school systems, welfare agencies, rehabilitation services, state institutions, medical institutions, family and social agencies, etc.

3. Parent and Friends Association

The general membership and sponsors of Parents and Friends of Mentally Retarded Children of Bridgeport, Inc., and Kennedy Center is made up of parents of retarded children and other individuals who are considered as "friends" of the retarded. Through a Board of Directors, elected annually in November by the general membership, they establish the policies used in the operation of the organization and the Kennedy Center. Any parent or friend who is a member in good standing is entitled to vote and to be elected as an officer or member of the Board of Parents and Friends. In January each year the President, with the approval of the Board, appoints over 40 committees to carry out the many purposes of the organization. These committees are made up of the membership and supplement services provided by the staff.

4. State relationships and other affiliations

One main objective of the organization is to promote the passage of favorable legislation on the state and local levels. Legislative action of specific concern is that which deals with educational opportunities, direct financial assistance, adequate institutional facilities, residential centers. Parents and Friends has been instrumental in the passage of many noteworthy Bills such as the creation of a State Office of Mental Retardation and the Mandatory Education Law, effective in 1961.

The organization is a member of the National Association of Retarded Children, the Connecticut Association of Retarded Children, and the National Association of Sheltered Workshops among others. It is also a member of the Milford United Fund and the Easton-Fairfield County United Fund.

5. New Construction - Kennedy Center

The next major aim of Parents and Friends is to construct its own specially designed building for the retarded to replace the present Kennedy Center which has become inadequate. The new Center will be 16,000 square feet in size, as against the present 3,600 sq. ft., and will be located on 5 1/2 acres of land on Virginia Avenue, leased by the City

of Bridgeport at \$1.00 per year. The construction will be facilitated by a \$100,000.00 construction grant from the Federal Government's Hill-Burton Program.

The entire cost of operation is approximately \$125,000.00 per annum (1962). Approximate sources of income to meet the operating expenses are as follows: United Funds and Donations - 40%; State Grants-in-Aid - 23%; Fees to families, other agencies, Government, etc., for services rendered - 25%; Vocational Training Income - 8%; Miscellaneous - 4%.

The general membership and community is kept informed of the activities of the organization and of important events in the field of mental retardation through a monthly bulletin called "The Crusader".

APPENDIX III

THE NEW KENNEDY CENTER BUILDING*

The new Kennedy Center Rehabilitation Facility is currently under construction and is scheduled to be completed no later than November 1, 1963. The facility specifically designed for mentally handicapped will cost approximately \$400,000 furnished and will contain some 22,000 square feet.

The building will be on a five and one-half acre tract located in the northeast section of Bridgeport, Connecticut. The site was made available to Parents and Friends for for 50 years by the City of Bridgeport at a fee of \$1.00 per year.

Of the construction costs, \$100,000 will be in the form of a construction grant from the Hill-Burton Program of the Public Health Service. All programs of the facility were reviewed by the Bureau of Vocational Rehabilitation in relation to the actual construction plans. The structure will be made of pre-cast concrete and will have two separate ground levels to conform to the terrain. The lower ground level will house the Administrative Offices and the Diagnostic Clinic. The upper level will contain comprehensive physical facilities for the various training and rehabilitation programs as well as an all-purpose room that will serve both recreation area and a small auditorium.

The design of the building is such that it meets the very specific needs of the mentally retarded children and adults. It should be remembered that since the mentally retarded are subject to the same physical handicaps and illnesses as other people that the design must provide for multiple handicapped individuals. The modular type corridorless design allows for a very flexible use of the building which is most essential when one considers that the field of mental retardation is constantly changing with emphasis being shifted frequently as new methods in habilitation and rehabilitation are found.

The new building will bring about a greater integration and coordination of staff and services, since the first time, all services and programs of the agency will be located in a single building. Such services as medical and dental examinations and laboratory work-ups are not being carried on in the physician's offices. The Vocational Training Unit and Sheltered Workshop are located several miles from the Center in an area leased, at no charge, by the Bullard Co. Another factor which will be alleviated will be the crowded conditions in the present Center which often require the use of rooms in shifts by the personnel. The agency will be in a position to render programs of great quality with a competent and experienced professional staff.

The new facility which will serve 250 children and adults will be the first known community Center in the country to be specifically designed to meet the total known needs of the

* This item was prepared in 1963 and was included in the Project Proposal dated October 1963, unpagged Appendix of Proposal.

retarded. Although it is planned as a complete rehabilitation facility, the philosophy of keeping the retarded in the community will be followed and integrated programs will be maintained with all other community agencies having related services.

The modular type design and the land available at the new building will allow for continued expansion of the programs for the foreseeable future and it was with these thoughts in mind that the present building program was adopted by Parents and Friends.

The new building will provide the necessary facilities and working conditions to allow for the most comprehensive demonstration project related to the habilitation and rehabilitation of the mentally retarded in a community facility.

APPENDIX IV

EXISTING RELATIONSHIPS WITH OTHER COMMUNITY AND STATE AGENCIES AND OTHER RESOURCES*

Educational Institutions and Agencies:

The public schools of Bridgeport and the six neighboring towns, covering both retardates diagnosed as educable and trainable retarded and those with undifferentiated diagnosis. There is close rapport in the discussion of curricular and extra-curricular matters, and an effective working relationship in the placement and supervision of individual pupils. Several of the systems rely for diagnostic evaluations and other forms of consultation on the Kennedy Center Diagnostic Clinic and program staff. The Superintendent of Schools in Bridgeport and the Director of Psychological Services in the Trumbull School system are both members of the Board of Directors of the Parents and Friends.

Approximately 15 - 20 specially selected high-school girls serve as volunteer workers at the Center annually. Center personnel take part annually in Career Day programs at the local high schools.

A variety of working relationships is maintained with four institutions of higher education, including two in the Greater Bridgeport area. Two members of the psychology faculty at Fairfield University, including the chairman of the department, are members of the Kennedy Center Diagnostic Clinic Staff.

Student nurses at the University of Bridgeport School of Nursing observe Kennedy Center programs as a part of their pediatrics training, and students in the Secretarial Division serve as volunteers in training at the Center on a regular basis.

Undergraduate students in the Special Education Division of Southern Connecticut State College are assigned to Kennedy Center as a regular part of their field-experience training, while numerous graduate students in special education at the same institution have spent varying periods of time observing the Center programs.

A graduate student in the School of Social Work of the University of Connecticut will be assigned full-time to Kennedy Center starting in September in fulfillment of a major portion of her field work toward a master of science degree in social work. Previously students from the same school have been assigned to Kennedy Center on a part-time basis. A variety of other relationships has been maintained with the School of Social Work for several years.

* This item was prepared in 1963 and was included in the Project Proposal dated October 1963, unpagged Appendix of Proposal.

Governmental departments and agencies - state:

Responsibility for supervision of state-operated facilities and programs for the mentally retarded is vested, under legislation passed in 1959, in the Office of Mental Retardation, a division of the State Health Department headed by a Deputy Commissioner of Health. The intimacy of the relationship between Kennedy Center and the O.M.R. is attested by the fact that the impetus for the legislation establishing the O.M.R. came largely from Kennedy Center. Moreover, the former Executive Director of Kennedy Center until recently filled the second-ranking position in the Division, Director of Community Services. (He was recently promoted to the position of Superintendent of a community residential and day-care facility to be operated by the City of New Haven.)

Kennedy Center maintains a close working relationship with the O.M.R. on virtually a day-to-day basis. In addition to its administrative and training responsibilities, the O.M.R. supervises state grants for community programs in the field of day-care, diagnosis and vocational training, Kennedy Center is currently receiving state funds in these areas of activity in the total amount of \$32,500 annually.

The O.M.R. is the responsible administrative agency for the Southbury Training School, which is one of two training schools for the mentally retarded in the state. The Kennedy Center staff and individual members have long maintained a wide variety of relationships with Southbury from the Superintendent and Board of Trustees down to the cottage attendants. Formal, established working relationships between Kennedy Center and Southbury are as follows:

1. Referral of prospective admittees to the Center for diagnosis.
2. Consultation and other forms of cooperation in programming and services.
3. Assistance by Kennedy Center in the supervision of Southbury residents on community placement.
4. Use of office facilities at Kennedy Center by Southbury case-workers.

Other state departments and agencies with which Kennedy Center has established working relationships are these:

State Welfare Department -- diagnostic services, consultation with caseworkers dealing with families which have retarded or children slow of learning and suspected of being mentally retarded.

Bureau of Vocational Rehabilitation -- provision of vocational training observation and evaluation services as well as medical, psychological diagnoses, through Diagnostic Clinic evaluations.

State Park and Forest Commission -- through the Connecticut Association for Retarded

Children, cooperation in the operation of a residential summer camp for the retarded at Harkness Memorial Park in Waterford.

State Department of Health -- occasional dealings with divisions and bureaus other than the Office of Mental Retardation. In particular the Hospitals Section in conjunction with Hill-Burton construction grants.

Medical and Hospital

In steadily increasing numbers, members of the medical community have called upon the Diagnostic Clinic and other departments of Kennedy Center ever since its establishment in 1956. In several recent instances, a newborn infant tentatively diagnosed by the attending physician as mentally retarded was referred to Kennedy Center even before the mother and infant left the hospital. The relationship has, of course, been reciprocal. The Diagnostic Clinic staff annually refers numerous cases to various medical specialists. In its first year, the Clinic was officially recognized by the Bridgeport Medical Society as a professional diagnostic facility. A pediatrician in practice in Bridgeport serves as medical director of the Diagnostic Clinic.

Both major general hospitals in Bridgeport -- Bridgeport and St. Vincent's, assign student nurses to Kennedy Center as observers in their pediatric year, as does the University of Bridgeport. The Department of Neurology at Bridgeport Hospital provides electroencephalogram and other services to the Kennedy Center Clinic on a regular basis.

Working arrangements with the Crippled Children's Workshop and the Cerebral Palsy Center, providing for various forms of physical therapy for retarded children and adults, have been highly successful. Cases are also regularly referred to the Bridgeport Speech and Hearing Clinic.

A staff member of the Child Guidance Clinic serves as both leader of a group therapy program for retardates with overlays of emotional disturbance and as a consultant to the Kennedy Center Clinic. Close cooperation also obtains with the local chapter of the National Association for Mentally Ill Children, particularly in the area of functionally retarded children with autistic symptoms.

A close relationship is maintained with the City of Bridgeport's Division of Humane Affairs, which includes the former Health Department. The Center and the Division worked together in initiating a city wide comprehensive preventive program providing for the testing of infants for phenylpyruvic oligophrenia. The Division director, a physician, has a keen personal interest in mental retardation and Kennedy Center.

Referrals are regularly received by the Kennedy Center Clinic from the Child Study Center of Yale University and Grace-New Haven Community Hospital. Upon completion of its diagnosis, the Child Study Center refers families of the retarded residing in the Bridgeport area to Kennedy Center for enrollment in Center programs or assistance in planning regimens for their children.

Other Community Agencies:

United Fund -- The Kennedy Center has received a grant annually from the United Fund. For the current year, the amount is \$45,850. The agency is also an active member of the Community Council, which is the planning arm of the Fund.

Goodwill Industries -- Numerous retardates in the Kennedy Center Occupational Training Unit have been placed in the Goodwill program, and there is continuous close cooperation between the agencies.

The Sheltered Workshop, Inc. -- Parents and Friends was one of the early sponsors of this agency, and a successful reciprocal arrangement has been maintained for approximately ten years.

Family Service Society -- Kennedy Center has cooperated with caseworkers from the society in numerous cases over the past several years. There are also similar relationships with the Social Service Bureau of the Roman Catholic Diocese of Bridgeport and the Jewish Welfare Bureau.

Boy Scout and Girl Scout Councils -- Boy Scout and Girl Scout Troops are sponsored by Kennedy Center, and the two Councils have provided various forms of special assistance to these.

Jewish Community Center and Y.M.C.A. -- Both agencies have provided their facilities and personnel on numerous occasions for special programs for retarded children and young people.

Religious denominations -- Special religious classes are sponsored by Protestant, Jewish and Roman Catholic churches as a result of the initiative of committees of the Parents and Friends. Parents of retardates play an integral role in both these programs.

APPENDIX V

JULY 1966 PROGRESS REPORT FOR THE PROJECT TO DEMONSTRATE COMMUNITY-BASED SERVICES FOR THE RETARDED

November 1, 1965 - July 15, 1966

Parents and Friends of Mentally Retarded Children of Bridgeport, Inc. (Kennedy Center) has a Vocational Rehabilitation Administration Demonstration Grant, now in its third year. During this period, a number of factors have had an influence on the demonstration, and a number of community situations have been influenced by the demonstration. Although this is a progress report for the year November 1965 through July 1966, it must be viewed within the total context of the project to date.

This year has been most significant since it produced an upheaval in organizational administration -- a difference arising between Staff and Board, and among the Board. To view the problems which developed in proper perspective, an examination of the implementation of the Project must be made.

The initial philosophy proposed by the individual hired as Director -- as reported verbally -- was to set up the Project disassociated from the organization to which the project grant had been made. In this manner, the Project personnel could function as "advisors" to the Association -- which was to be viewed as just another agency in the community. Although this may appear as an appropriate method, it must be viewed both within the framework of the organizational administration, and the personalities of the individuals involved.

The Director of the Project came to the Association with a background of extensive service in the field of mental retardation. He had served as an executive director of a state parent association which had played a leadership role in development of programs in the state as well as the nation. He came into an organization which had a relatively new executive with no previous experience in the field of mental retardation or in parent association. This writer, who was then serving as Director of New Haven Regional Center for the Retarded, was visited by the Director of the Project prior to his final commitment to the position. This writer suggested that if he took the position he would have to consider the probability that he would also wind up acting as executive director, since through his experience and training, Staff and Board would look to him for guidance. His feeling was that by disassociation -- separate staff and offices -- this need not occur. Through periodic visits to the community and occasional visits from the director to this writer, it became apparent that the strength and personality of the project director was, in fact, making him the individual to whom most Board and Staff were turning for advice. The executive director of the Association seemed to become more withdrawn from the organization as the project director became more involved.

With the Project set up in separate offices, it was in effect representing itself as a separate part of the organization, but the community found it difficult to disassociate the Project from Kennedy Center. It was also difficult for the organization to view the Project as separate from the Association program services.

When an organization as dominant and aggressive as Kennedy Center is, and has been, in providing basic services for the retarded in rehabilitation, clinical diagnosis, day care, recreation and public information about retardation secures a VRA Demonstration Project to broad-base these services, the Kennedy Center would have to be the unit prepared to discontinue programs as other agencies could be encouraged to assume the responsibility.

During the period of personality-and-training assertion of the Project Director, and the diminution of the Executive Director (with the Project Director meeting the community people without the involvement of the Executive), the Kennedy Center was also in the throes of expanding itself from a small, self-constructed building of 3600 square feet, to a new plant under construction with approximately 24,000 square feet. The Association was in the process of raising \$300,000 for this building and completely preoccupied with this program.

On one hand, the Project was recommending other agencies assume programs; on the other hand, the Association was building a new plant to provide greater program space. Although this may seem a paradox, the needs of the retarded are so great, with the demonstrated reluctance of the community agencies to move quickly to meet needs, the Association could justify the need for the building and the Project. As the pressures of the building and program services needs grew and the building program was completed, the need of the Association for dynamic, imaginative leadership became more and more obvious. A greater discrepancy also became evident between the Project Director and the Executive Director. Members of the Board of Directors felt this had to be resolved and a resignation was submitted by the Executive Director of the Association. Since the Association and staff had been relating more to the Project Director, it would have seemed at this time logical for the Project Director to assume the executive responsibilities, also. However, at no time would he agree to this and insisted on maintaining a separateness of Project and Association. An acting executive was appointed who was an employee of the Association and who looked to the Project Director.

While this was occurring, the Project -- which had an Advisory Committee made up of representatives of the Association and its Board, professional members from throughout the State, and lay leaders in the community -- continued to develop demonstration programs in the community and with community agencies. At the same time, the Association committees in program services continued to function and also looked for avenues of development and implementation. This began to cause some feelings within the organization between parent members and the professionals in the Project.

About this time another major factor developed within the Association. A relatively "new" member was elected president. Since the founding of the Association in 1951, a core group of people, parents of retardates, were the leaders of the Association, and generally the key members of the Board and the committees. Within the organization there was some feeling among "old" and "new" people and the newly-elected president felt "new"

members should become more involved. Among professional workers in the field, there is also considerable feeling about Parent Associations and "emotionally" involved persons directly responsible for program development. The implication is that "emotionally involved" people tend to allow these emotions to govern their decisions in developing services. In the philosophy of some professional persons, there should be little direct parent Board of Committee participation in program development, but a power structure of community people should consult in this area.

Although the "new" president was a parent, she was also a "professional", working full time as an elementary school teacher. Between the Project Director -- who felt the parents should be spread out and other non-affiliated persons should be brought in as Board and committee people -- and the President who felt the "old timers" should be moved over and new parents and non-parents brought into positions of responsibility -- a natural alliance was formed. With the vacancy of the Executive Director's position, the Project Director and the President assumed many of the responsibilities of the Executive, even though there was an acting executive.

The Association was actively recruiting for a full-time executive. A six-month period transpired before the Association hired an executive. Once again, the individual came to the Association with no previous experience with mental retardation or a parent association. The Project Director would naturally become the executive's resource person, and yet the Project Director still insisted that the Project and the Association remain separate entities of identification through the maintenance of separate offices and continued development of programs as a project separate from the Association services.

Within the Association the Project was also demonstrating program development through diagnostic resources and vocational rehabilitation. The Project financed positions to bring into the Association experienced personnel to improve the services, to demonstrate to the community effective differential diagnosis of retardates for recommended placement in other community program resources and rehabilitative productivity for competitive employment.

Another major problem developed in this area. In order to find experienced personnel in diagnostic services, those individuals available had to come from other handicapping population interests. The primary recruitment group was in mental health.

Interestingly, when parents of the retarded were fighting their battles to secure services in the early years of the movement and turned to child guidance and mental health services, they were generally turned away. When Federal and State funds became more readily available, there was a "band wagon" reaction from the professional resources. The Project recruited as Director of the Clinic, a psychologist out of a mental hospital program. As Clinic Director he felt the Clinic should have total control of the referrant. The Project Director and the Executive Director felt they needed to have some say in the program recommended for the family and the child. In effect, what was being created was a three-headed monster, each struggling to reach the definitive role in the Association. In addition, the parents of the Association, who still felt they had a policy role to play, were also struggling for a role in the program.

The vocational training program (which had been moved from an industrial setting to the new building) was not working out because of space and inherent construction problems, and was moved back into an industrial location. A Workshop Director was recruited who brought with him a highly paid productive sub-contract from out of state. It was the philosophy of the Project and the Workshop to create a vocational training unit which could demonstrate financial self-sufficiency. In order to accomplish this, however, the minimal producer had to be programmed out of the services. This caused great consternation among parents whose young adults had been participating in the program for a number of years.

With the new building, additional staff, and a federal project, questions were being asked by the membership regarding what seemed to be less services being provided to the retarded than when there was a smaller building and less staff. Other groups of retarded were having opportunities opened to them through creation of expanded services in conjunction with public school resources.

While all these conditions existed, new developments outside the Association were also occurring. The Association had played a major part in conjunction with the Connecticut Association for Retarded Children, in the creation of the Office of Mental Retardation and the philosophy of the Regional Centers. The first three were created in Waterford, Hartford and New Haven. This was followed in 1963 with one in Putnam. In the 1965 Legislature, requests were made to create Regional Centers in Bridgeport, lower Fairfield County, and Torrington. It was felt by most Association leaders that these centers would not be approved in this session. In order to assist the Legislature to favorably consider the creation of the Bridgeport Center, the Association, with the consent of the community leaders who helped raise the funds, volunteered to donate the newly-constructed center to the State in consideration of payment of \$75,000 outstanding mortgage. It came as somewhat of a surprise that the Legislature approved all the three new centers.

This caused some immediate planning by the Association to make a transition to new quarters and revised programming concepts. The Project offices, previously located in a building which was sold, had moved to a new commercial building complex. When the sale of the Kennedy Center building to the State was being completed, the Project Director and the Executive Director suggested the two programs now move into the same office space in the commercial setting. The offices of the Association and the Project were combined in the new location and the Clinic was also relocated in the same offices. The Bridgeport Regional Center assumed the building in which the Association had been located and also the day care program. Some staff members of the Association were hired by the State and the vehicles for transporting the children were purchased by the State.

With this move, a resurgence of the Project control of program development took place, with a contrary feeling on the part of the "old" members. The Project Director and the Executive Director took -- with the support of the President -- a more aggressive role in making decisions as to what kind of programming should be done for the retarded.

At a general meeting of the Association, at which time the Workshop staff was to report to the activities of the program, a major issue was raised by parents whose children were participating in the program, but because of their degree of retardation were being moved

out as non-producers, an intensive emotional reaction on the part of many individuals caused the Project Director to have serious doubts as to the future effectiveness of the organization.

During previous meetings with the Project Committee, there had been discussion of the establishing of an institute for training sub-professional persons in the field of mental retardation. Following the general meeting, a committee of two volunteers was recruited to consider the possibility of creating an independent non-profit association to make application for this institute. When the Association learned of this, they felt that this was violating the relationship between the professional staff and the Association. The hostility between the Board members and the professionals was too great to overcome and the Association requested the resignations of the Project Director and the Executive Director. The President resigned in protest and the Vice President filled the position until the new elections.

At this, the President-elect assumed the responsibility of working with the staff, visiting the offices daily. The Association held a dinner for all staff to become acquainted. The Association then continued recruiting for an executive director and project director.

The writer, having completed the construction and initiation of the program of the New Haven Regional Center, feels the State program has the potential of providing broad-based residential and training programs, but suffers the limitations of various State and financial restrictions. The role of the parent association and the community must continue to be dynamic and flexible to meet needs the State-supported program cannot, or until such time as it can.

When asked by the President of the Association if he would be interested in the executive directorship, the writer felt this would be the opportunity to demonstrate the parent, community, state and federal cooperative relationship for programming and agreed to accept the position on condition the Project and Executive Directors' positions be combined. The writer started with the Association on May 2, 1966.

All during the previous stages of the internal developments of the Association and Project relationships, progress was being made in getting the community to extend its base of service.

The new Bridgeport Regional Center began operation on October 1, 1965, as a State agency. This assumption indicated that the direction and scope of the program was recognized by the State of Connecticut, which was able to create a Regional Center in Bridgeport because of the hard work and planning that had been done by the Parents and Friends group and the Connecticut Association for Retarded Children.

With the State's assumption of the building, they also assumed program responsibility for the day care services existing in the building. Because the legislature moved more quickly than anticipated, in 1954 funds were not appropriated for other activities conducted by the Association. The diagnostic clinic still had to be funded by the Association. The Workshop program which had started in the building had to be moved and continued to be admini-

stered, supported and staffed by Kennedy Center.

At this stage in the development of community services, the State is planning to construct intensive care units in Bridgeport for severely and profoundly retarded, and Kennedy Center and the Office of Mental Retardation is engaged in an intensive search for land to expand the existing Regional Center program.

Each year the Lane Bryant Award goes to an organization for outstanding volunteer service to the community. In November 1965, Parents and Friends of Mentally Retarded Children of Bridgeport, Inc., received this award for the year 1964. The nomination was made by the Governor of the State of Connecticut.

* * * * *

(Summaries of "Present Kennedy Center Programs" were then presented, in the following format: (1) Kennedy Center Clinic, (2) Information and Referral Service, (3) Recreation Programs at Kennedy Center, (4) Leisure Time Activities, (5) Faust Hall, (6) Girls' Residence, (7) Project TRI-US (Training Retarded Individuals in Useful Service), (8) Enriched Day Care, (9) Kennedy Center Workshop, (10) Educational Work/Experience Program, (11) State Level Participation, (12) Summer Traineeship Program.)

The establishment of a Regional Center in the area has created a working partner with the Kennedy Center and will give Bridgeport support in the problem of establishing comprehensive services. The Regional Center and the Parents and Friends organization will have to coordinate very closely their combined efforts in the area of new service development. The timing and sequence of this development has made a great impact upon the establishment of the "Continuum of Care".

It will be important to establish a division of responsibility, methods and procedures for communication and a mechanism for planning. Particular emphasis will be placed upon developing further components of the comprehensive service model and establishing systems and procedures for the "spectrum of opportunity".

In all communities, the demand for and need for service continues to increase. The problem at this point is not only that present services cannot handle the numbers in need, but that the present variety of services are incapable of meeting the specialized needs of this complex and heterogeneous group of handicapped individuals. As a result, much of the benefits of service given to a retardate may be lost when his changing service requirement is not available. The path toward fullest potential is blocked. The community-based spectrum of opportunity must be achieved if we are to meet the changing needs of the retarded.

Potential Expansion Areas for Kennedy Center

1. In-service training for Kennedy Center staff and the development of the in-service training programs and curricula for other professional disciplines and agencies.
2. An examination of current Kennedy Center programming and an investigation of other agency services which could be expanded to provide these programs.
3. Procedures and techniques in the management of Faust Hall and other residential units to develop a method by which they can be fiscally self-sustaining.
4. Establishment of girls' residence to be opened in November 1966.
5. Development of a guardianship and protective services program.
6. The investigation and demonstration of a productive employment center for community non-successful job seekers.
7. Development of training programs for vocational clients in areas not normally considered productive for placements, such as sales and home service programs.
8. Development of foster grandparent program.
9. Intensive program development in areas of parent education and clinically therapeutic treatment programs for parents.
10. Development of a treatment program for disturbed retardates.
11. Involvement of such groups in religious and recreational services.
12. Development of curricula for counseling of parents and children in areas of sex education.
13. Development of a program to meet the needs of non-English speaking mentally retarded community residents, oriented to the Puerto Rican population.
14. Development of a language, speech and hearing program and an investigation as to how communication affects the job potential of a retarded adult.
15. Development of a regional residential and day camp facility.
16. Stimulation of the community to adopt the Information and Referral Service.
17. Training institutes in cooperation with colleges and universities in the area.
18. Expansion of college and university curriculum to include special education courses.

19. Development of a public education program oriented to work placement for retarded adults.
20. An investigation of the needs and program services or the economically and culturally deprived mentally retarded population in conjunction with the Office of Economic Opportunity Development.
21. Expansion of community-based programs implemented on a statewide basis.

APPENDIX VI

PARENTS AND FRIENDS OF MENTALLY RETARDED CHILDREN OF BRIDGEPORT, INC.

4695 Main Street

Bridgeport, Connecticut 06606

1968 ACCOUNT OF THE HISTORY OF THE ASSOCIATION*

The Parents and Friends organization, with administrative offices at 4695 Main Street, Bridgeport, is a thriving, growing organization. They can point with justifiable pride to the acquisition of two large residences for men and women; comfortable administrative offices; a well-qualified staff; and outstanding workshop, well-equipped with various types of tools and machinery; a unique service-oriented training program; even a few older, but serviceable vehicles for transportation. But like most non-profit organizations they are experiencing the difficulties of changing trends in government funding and the growing multiplicity of appeals for contributions from private sources.

Seventeen years ago a small group of Bridgeport parents, twelve in all, banded themselves together, determined to seek out ways of securing suitable training and care for their mentally retarded children. Originator and spokesman for the group was Mrs. John P. Kennedy, herself the mother of a retarded boy, and searching desperately for an alternative to sending her son to an institution. From this nucleus has grown the nationally known "Kennedy Center" or to use the legal, corporate name, Parents and Friends of Mentally Retarded Children of Bridgeport, Inc.

The far-reaching effects of that first meeting remind one of the constantly widening ripples caused by a small stone cast into a pond. Seventeen years ago no one talked about mental retardation; this valiant group set out to make it a household word.

The first public school class in New England for trainable children was started because of their appeals to the superintendent of Bridgeport schools. Their efforts, combined with other like-organizations, resulted in Connecticut establishing the first separate Office of Mental Retardation in the United States. With little money, but tremendous quantities of physical labor, and sublime faith in themselves and the goodness of their fellowmen, they erected the first parent-owned community center building for retarded children unable to attend public schools. This was followed in less than ten years by the erection of the first fa-

* This item, from association files, was prepared September 5, 1968 as part of a presentation to the United Fund of Milford.

cility of its kind especially designed to meet the needs of a non-residential agency working directly with retarded children, the Kennedy Center on Virginia Avenue, Bridgeport.

In 1965, when the State legislature voted to establish seven regional centers for the mentally retarded, members of Parents and Friends in an unprecedented action, voted to make an outright gift of this newly-opened building in order that state-sponsored services might be available to the children of this area at least two years sooner than would otherwise have been possible.

The original and continuing reason for the organization was the parents' desire to secure education and training services for their children on an equal basis with normal children. Of equal importance was their desire to keep their children at home, or as close to home as possible. Regional centers answered at least a part of this desire.

At varying times in the past 17 years, they have established such services as day-care classes; a diagnostic clinic which included the services of a physician, dentist, psychologist, and speech and hearing therapists; recreation programs; summer camping programs; vocational workshops; and two residence for men and women. The investment in property and equipment, alone, was a staggering financial burden, as was the necessity for employing a fair-sized staff of professional and administrative personnel.

Official recognition of their accomplishments was accorded Parents and Friends when they were awarded a five-year grant of approximately \$500,000 by the Department of Health, Education and Welfare, for the purpose of "demonstrating comprehensive community-based services for the retarded". This grant is now in its fifth and final year, and the cessation of income amounting to more than \$80,000 a year presents many problems to the organization.

Where is the money to be found? One obvious answer is to reduce the expenses of the various program services. The administrative staff under the direction of Mrs. Marie L. Gall, executive director, has been reduced to five persons. As provided in the demonstration grant, the Association has confirmed in many ways, the willingness of other agencies, public and private, to assume the responsibility of many of the programs they had started. After two years of joint effort, the YMCA has assumed responsibility for providing day camp facilities for the mentally retarded. Speech and hearing therapy and diagnostic evaluations are available for the school age child at the State-sponsored Bridgeport Regional Center, thus enabling Parents and Friends to phase out their diagnostic clinic. Many civic and fraternal organizations contribute varying sums to partially support such activities as the recreation programs. But some services are not so readily transferable.

In the development of Kennedy Center services, the creation of a workshop program for young adults was a more or less natural outgrowth. From a modest beginning in the basement of St. Patrick's school, this workshop has advanced through various stages until it now occupies several thousand square feet of space in an industrial building at 480 Bunnell St. In the year 1967, an average of 60 young men and women produced \$44,900 of subcontract work for which they received wages of more than \$33,000. "The contracts for this work come to us", said Wes Norton, Workshop manager, "not as an act of charity, but simply as good business." When a request is received for a job to be done by the Workshop, the price

to the contractor is figured in much the same way any manufacturer figures his costs, including a fair overhead charge. Many area businessmen are delighted to make use of the Kennedy Center Workshop services, knowing that the shop lives up to all the rules and regulations of the United States Department of Labor.

During the time a young man or woman is employed at Burnell Street, he is continually receiving training that will, hopefully, prepare him for a job in the community. Good work habits, good personal habits, punctuality, traveling by public transportation, getting along with fellow-workers, safety habits, are all training areas for the Workshop employee. While in the Workshop he is covered by Social Security and pays income taxes on his earnings. A far cry, indeed, from spending most of his life in a tax-supported institution!

Despite all this training, there are some young people who are just not adaptable for a job in private industry. The reason may be physical, emotional, or a more severe degree of retardation, but the hard inescapable fact remains that here are people who cannot fit into the norms of accepted behavior in a job situation. Yet, he may be capable of producing acceptable work at a slower pace, or possibly under closer supervision. For this person continued employment in a sheltered workshop is the only answer. There he is happy, he is working amongst his peers; is gainfully employed; he is a person -- and he needs the Workshop. To close out this service to the retarded would be unthinkable.

But mental retardation ranges from the mild to the severe -- from the individual who is totally helpless to those who can become wholly or partially self-supporting. Formerly, institutional placement was the only answer for the severely retarded; now there is an alternative. The Kennedy Center TRI-US program is that alternative for 60 men and women from 16 to 59. The name TRI-US stands for Training Retardates in Useful Service, and it is truly descriptive of its purpose. It has been estimated that four out of every thirty retardates will always be at least semi-dependent and these four out of thirty have been largely the forgotten people in mental retardation. Incapable of reading or writing, often with little or no speech, sometimes incapable of caring for their simplest personal needs, they were either on a waiting list for state institutions, or merely sitting around at home, perhaps staring blankly at a television set, scarcely comprehending what they saw. For this type of retardate and others, Parents and Friends once more prepared to "tilt at windmills." A special grant application and plan was written, entitled "Demonstrating New Directions in Community Programming for the Mentally Retarded Adult," and the Department of Public Health agreed to partially fund the grant for a period of five years.

Because of their pioneering spirit and willingness to expend time, services and money, leaders of Parents and Friends have always attracted professionals from many fields. In the planning stages of Tri-Us, Miss Bernice Vennert joined the staff, dynamic, outspoken, forthright in her declaration that "these too are God's children," she was easily the logical choice for director. She possessed an exceptional educational background but, more importantly, was formerly the nursing director at Monson State Hospital in Massachusetts where she established many training patterns for dealing with the multiple handicapped which are still in use today.

In the beginning, the parents were skeptical, their sons and daughters had for so long

been kept in the background, they were sure nothing could be done. A lesser woman than Bea Vennert would have despaired of results when her first trainees were admitted to the program. In some cases, so little activity had been provided, they had even forgotten how to walk! Caring for their personal needs was almost unheard of, as was the thought that these men and women could perform useful and necessary tasks. The creed of the program -- spoken and written -- was "everyone can do something; you just have to find out what it is."

First came the training in caring of their personal needs; the girls were taken weekly to the beauty parlor; the boys were taught to shave and comb their hair; all were impressed with the necessity for coming to the program dressed neatly and cleanly. From simple household tasks, the trainees progressed to clean-up yard jobs, washing and painting walls, shopping at a nearby A & P. After many, many months of training, they even began to help in maintenance work at low cost housing projects in the city. With the proven success of the program, more and more applications were made for admission until there are now 60 enrolled and several more on a waiting list.

Unfortunately, after two years of participation, the Public Health Service felt the program no longer qualified for grant funds and this source of revenue was cut off, placing a tremendous burden on the Association. While a very few of the Tri-Us trainees can use public transportation, it is impossible for most, and so they must be picked up at their homes and returned at the end of the day. Since the job training areas are scattered throughout the community, it is necessary to drive the work groups and supervisors to and from jobs -- a high cost item. Tri-Us is the only program of its kind in this area: (it may well be the only one of its kind in the country, but the staff has always been too busy to make certain of this!) consequently, the trainees come from outlying communities. Transportation and Tri-Us training services are provided to clients in Bridgeport, Stratford, Trumbull, Monroe, Fairfield, and Milford, with at least one client coming from an area very close to West Haven. We know that the yearly cost of keeping a client in this program is approximately \$1,300 per person.

When the parents were informed that there was a strong possibility we might have to terminate Tri-Us, they readily agreed to pay a weekly fee, insofar as they were able, to keep the program alive. Tri-Us trainees had been working for many weeks under the supervision of a registered nurse on the Kennedy Center staff, at such places as Hillside Hospital and Margaret Ford Cottage. Since these were considered training areas, no payment had been requested for these services. Now it became a vital necessity and Bridgeport city officials agreed that the organization should be reimbursed in the future. Similar appeals were made to the building management of the public housing areas and a fee was set. Nevertheless there still remains a wide gap between expense and income.

Staff and Board members realize the importance of this program not only to the clients but to the community. With industry requiring fewer unskilled workers due to automation, the need for the "odd job" person is becoming acute. The Tri-Us worker is trained for such household jobs as window washing, floor scrubbing and polishing, lawn cutting, snow removal, etc. The mobility of the Tri-Us workers and supervisors - going to where the work is - should be a decided asset in performing odd jobs for individuals and small companies. While these retardates will always require more supervision than others, they are performing tasks

which are useful to themselves and the community and the Parents and Friends feel they should be encouraged and supported.

Despite their present involvement with the program for the more severely retarded, this volunteer organization has never forgotten that comprehensive, community-based services must give consideration to the mildly retarded as well. Of particular concern were those parents who did not want their child living in an institution, yet realized that the average person could not financially provide a home for that child when the parents reached their inevitable end. The ideal answer to their fears would be a residential home in the community, reasonable in cost, with moderate supervision. In 1964, Parents and Friends set out to establish such a home and Faust Hall at 803 Clinton Avenue was the culmination of their efforts. This large, rambling, Victorian style home has been remodeled in accordance with existing fire and safety regulations; it is comfortable, and spacious enough for twelve young men who live there under the guidance of the houseparents, Mr. and Mrs. Ray Caron. They are all employed in the community and live much as any young man would live in his own home. There is nothing to indicate to the casual observer that, before Faust Hall, several of these boys had spent the greater part of their lives in institutions, simply because there was no place else for them to go. During the four years of its existence, many boys have adjusted so well to community living that they have been able to go out on their own in small apartments or furnished rooms. Whenever this happens, the Kennedy Center staff continues to keep in contact with the young man, making certain that he is included in all recreational events and social dances. If he requires personal advice or counseling, it is always available to him.

At 44 Brooklawn Place, only the inconspicuous sign, Maridot Manor, reveals that this is anything other than a very lovely private home. Here, eleven young women under the guidance of two housemothers are also learning to live and work in the community in much the same fashion as Faust Hall residents. Professional guidance is available for the young people and the mysteries of budgeting, cashing checks, shopping, cooking, and so on, are made understandable to them.

Both homes are somewhat self-supporting insofar as running expenses are concerned, with all residents paying an established weekly sum for board and room. The initial costs of purchasing, improving and maintaining the homes were the result of joint efforts by hundreds of people in the organization and in the community. One of the leaders in this effort was Warren J. Faust, for whom the home has been named.

Civic-minded businessmen have always been generous in their response to appeals from this group of people who were "helping themselves before they asked for help." Herculean efforts on the part of thousands of volunteers have brought sums of money, large and small, and Parents and Friends have conducted countless fund-raising events from cake sales to fashion shows. The Four Seasons Ball, sponsored by the organization and many women in the community, each year raises several thousands of dollars for expenses connected with Faust Hall and Maridot Manor. The name of the girls' residence is a combination of the first names of two of these outstanding women, Mary Faust and Dorothy Larson, both of whom played important roles in establishing and continuing the home.

The Connecticut Office of Mental Retardation and the Division of Vocational Rehabilitation also provide funds for certain aspects of the training programs.

In 1961 a thrift shop was opened as a means of raising funds for the organization. Under the leadership of Mrs. Stanley Swanson, followed by Mrs. Eugene Schneider, a large group of volunteers devoted hundreds of hours to establishing the "Nearly New Shop" at 903 Noble Avenue. So successful were their efforts that larger quarters had to be obtained in 1966 when the shop was moved to its present location at 1189 Barnum Ave., Stratford. Now under the direction of a new manager, Mrs. James Callahan, who is also a member of the Association, the shop hums with activity. In addition to providing additional funds for services to the mentally retarded, it also provides an opportunity for those with limited funds to obtain good, high-quality clothing and household items at reasonable prices.

Parents and Friends has been a participating agency in the United Fund of Eastern Fairfield County since 1955. An appeal to the budget committee for additional funds has resulted in the promise of a very generous increase if the forthcoming campaign is successful. All possible avenues of increased income are being explored.

Despite all these fund sources, despite the tremendous efforts of unsung volunteers; despite stringent control of expenditures, always the need is greater than the resources to meet it. Perhaps it is because the need is always present and always increasing. Mental retardation can never be considered a static problem, one to be met and adjusted to. It is not like a medical illness that can be cured or improved. And as the years go on it becomes increasingly difficult to raise money. It is fairly simple to raise money for children -- all children, including the retarded, are appealing. But mental retardation is not a condition that can be conquered, and children grow up to be adults. Until recently, no one talked much about the retarded adult. Most of the advice and care was geared to the baby, the child, possibly the teenager, but rarely the adult. Yet geriatrics is a problem in the mentally retarded just as it is in all segments of our population. We must provide for the adult retardate. Parents and Friends ask the question: "Do you know a better way of providing for him than caring for him, training him, and insofar as he is able, enabling him to become a self-respecting, participating, "sharing" member of our community?"

The answer to that question depends on the response of thousands of citizens as they consider their neighbors request for United Fund support. We pray it is the right answer.

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Mrs. Wallat proved uncanny in finding file material and excellently typed several of the manuscripts of the Writing Staff.

Mrs. Helen Powell proofread various manuscripts with care and devotion.

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Other current or recent Board members, active in the Parents and Friends, who provided helpful information or perspectives were Mrs. Gilbert Larson, Corresponding Secretary, Mrs. Warren J. Faust, Mr. John Lyddy, Mr. John Plavnicky, Mr. Fred Breul, and Mrs. James Riddell.

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Many other persons made themselves available, often repeatedly, for critical discussions. These included particularly: Mr. and Mrs. Eric Sandahl; Miss Ann Switzer, Executive Director, Connecticut Association for Retarded Children; Mr. Clifford P. Lockyer, Director, Bridgeport Regional Center; Dr. Ralph Welsh, Associate Professor, Fairfield University and former Director, Diagnostic Clinic, Parents and Friends; Mr. Edward Gernat, Chief Social Worker, Bridgeport Regional Center; and Mrs. Isobel Broadhurst, former President, Parents and Friends.

Discussions of special problems or events that were illuminating occurred with: Mr. Bert Schmickel, Deputy Commissioner of Health, Office of Mental Retardation, Connecticut

Department of Health; Mr. Arthur DuBrow, Director, Mental Retardation Services, Office of Mental Retardation; Mr. Joseph Marra, Chief, Bureau of Rehabilitation Services, Division of Vocational Rehabilitation, Connecticut Department of Education; Mr. David Barron, formerly Director, Speech and Hearing Services, Kennedy Center, now Director, Speech & Language Pathology, Southeastern Connecticut Hearing & Speech Center, Groton; Mrs. Rhoda Rosen, formerly Director of Volunteers, Kennedy Center; Mr. and Mrs. Ray Caron, formerly Houseparents at Faust Hall; Mr. Sheldon Smith, ACSW, Director of Social Service, Southbury Training School; Mr. Dwight Waring, Rehabilitation Counselor, Bridgeport Office, Division of Vocational Rehabilitation; Mr. Wesley Norton, Workshop Manager, Parents and Friends; Professor Ignacy Goldberg, Teachers College, Columbia University; Professor Gunnar Dybwad, Heller School, Brandeis University; Mr. Harvey A. Stevens, Superintendent, Central Wisconsin Colony and Training School; Dr. Burton Blatt, Assistant Commissioner for Mental Retardation, Massachusetts Department of Mental Health; Dr. Alexander Tolor, Research Institute, Fairfield University; Dr. Anthony Graziano, Department of Psychology, University of Bridgeport; Mrs. Lois Schneider, Social Worker, Rehabilitation Center, Bridgeport; Miss Bernice Vennert, R.N., formerly Director of Tri-Us, Parents and Friends; Mrs. Mabel Miller, Supervisor of Special Education, Stratford Board of Education.

Many others were interviewed, including: Mrs. Florence Dillon and Miss Helen Paull, Housemothers at Maridot Manor; Dr. James S. Peters, II, Director, Division of Vocational Rehabilitation, Connecticut Department of Education; Mr. Clifford Beebe, Consultant, Rehabilitation Workshops and Facilities, Division of Vocational Rehabilitation, Connecticut Department of Education; Mr. Robert Bain, Chief, Bureau of Community and Institutional Services, Division of Vocational Rehabilitation; Mrs. Rose Loughlin, Supervisor of Special Education, Bridgeport Public Schools; Mr. Walter Chop, Educational Planning Director, Bridgeport Board of Education; Dr. Paul A. Lane, Project Director, Bridgeport Vocational Rehabilitation and Cooperative Education Project; Mrs. Ruth Muldoon, Public Health Nurse Supervisor, Bridgeport Department of Humane Affairs; Mr. Salvatore Clarizio, Staff Psychologist, Bridgeport Regional Center; Mr. Edward Daley, Director of Recreation, Parents and Friends; Mr. Edmund McLaughlin, Executive Director, Rehabilitation Center, Bridgeport; Mr. Donaldson Tall, Director, Planned Parenthood, New Haven; Mrs. Mary Elizabeth Walsh, formerly Speech and Hearing Therapist, Kennedy Center; Mrs. M. B. Thompson, Program Director, Neighborhood Youth Corps, Bridgeport; Mr. Paul Littlefield, Assistant Director, Aid for Retarded Children, Stamford; Dr. Bruce Mueller, Consulting Psychologist, Rohrer, Hibler and Replogle Associates; Mr. Richard O'Connor, formerly Executive Director, United Fund of Eastern Fairfield County; Mr. Francis Donnon, Community Chest, Bridgeport; Mr. George Trent, Regional Supervisor, Division of Vocational Rehabilitation, Connecticut Department of Education; Edwin C. Kepler, formerly Executive Director, A.B.C.D.

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